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A Check List to aid Patient/Carer Memory Recall within the Medical Appointment: An Action Design Research Journey.

Michael B. Twomey

91158761

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Management Information Systems

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Supervisors: Prof. David Sammon and Dr Tadhg Nagle

Head of Department: Prof. Joseph Feller

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The Author hereby declares that, except where duly acknowledged, this thesis is entirely his own work and has not been submitted for any degree in the National University of Ireland, or any other University.

Acknowledgements

"No man is an island entire of itself; every man is a piece of the continent, a part of the main…" these words by John Donne (in his poem *"No Man Is An Island"*) spring to mind when I consider all of those that have helped make this PhD journey and it's outputs a reality.

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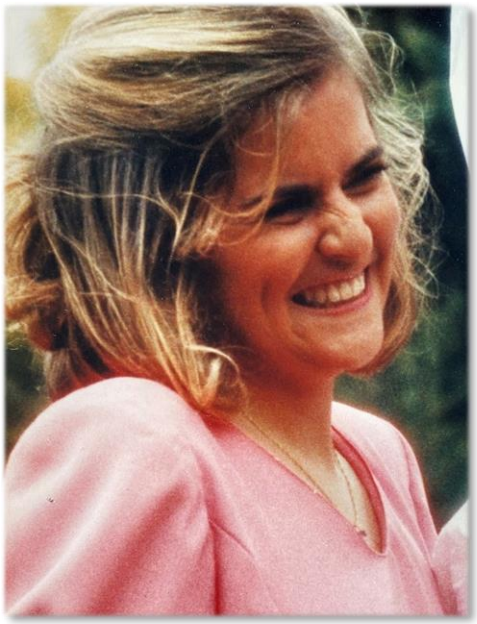
To my beautiful wife Liz, what can I say? You have been my rock. Thank you for being behind your husband's lunacy, beginning in 2017, a then 45-year-old aspiring to do a PhD, to make his own contribution to those who toil with CF. Thank you for your patience, reassurance and support, for believing in me, for loving me, even on *"those days when I was a little difficult"*. I adore you; you and your beautiful warmth are the reason that even the most difficult days were made more tolerable, made so much brighter, making me feel that anything was possible. I look forward with a renewed sense of eagerness to devoting a lot more time to you and our dear son Jack in the near future. You and Jack are everything to me.

Penultimately, to my dear son Jack, thank you for putting up with your dad spending so much time in his man-cave, doing his research, for bringing your own exclusive brand of infectious energy and happiness into said cave every day at 3pm, giving your *"old man"* the lift, he needed to endure the hours ahead. For your smiles, love, hugs, and playful wit, I look forward to playing more *"ball"* with you. I love you more than you will ever know.

Finally, I dedicate this PhD thesis to the memory of my dear sister Jane Twomey, who died with CF in 1997. Jane I will never forget your courage, your strength,

your remarkable spirit, as you toiled with CF on a daily basis. Amazingly, you never let it define you, or consume you, and even though you sailed your course with tattered sails, often struggling to catch the wind, you did so majestically, achieving so much in your short life, bringing so much joy and love to those around you. You never let your condition impede you from any pursuit you set your mind to. You were the fuel that ignited my quest, the example by which I set my compass. Indeed, the memory of your dear smile was (and still is) the vivid light that often guided my research endeavours, giving me the strength and the mettle to continue on, to navigate my ship safely ashore. Thank you for being my inspiration.



Jane Twomey

1968 - 1997

Abstract

The main nexus of communication between the patient/carer and the doctor is the medical appointment. The primary aim of which is arriving at a correct decision/diagnosis via information elicited from the patient/carer by the doctor. This bi-directional conversation regarding the patients' medical history (termed the *elicitation phase*), necessitates the retrieval of data from the patients/carers long-term declarative memory. Unfortunately, recollection for medical history, like other modes of autobiographical memory, tends to be defective, incomplete, and erroneous. Additionally, the ability of the patient/carer to recall (at a later date) what has occurred *within* the *elucidation/explanatory* phase of a medical appointment is also quite problematic. Such memory recall/information retrieval issues give rise to numerous pernicious effects, more especially, for the patient.

Taking an Action Design Research approach, the artefact designed, built, and evaluated to address the problem of poor memory recall is a pretotype (a paper-based prototype) in the form of a check list. The researcher in this study, a 48-year Cystic Fibrosis patient (who has experienced the problem of poor memory recall within his own medical appointments), decided to embark on a quest to ameliorate or remedy the problem. His practice inspired investigation became driven by the following motivation: *How might we augment Cystic Fibrosis (CF) patient/carer memory recall/ information retrieval within the elicitation phase and elucidation phase of the medical appointment?*

Rigorous evaluation by CF patients, carers and respiratory clinicians' points to the artefact's validity and shows its contribution to practice, by facilitating the capture

of specific CF related data collection *before* and *during* a medical appointment, enhancing a CF patients/carers ability to recall key clinical data *within* and *after* the medical appointment. Giving rise to reduced stress levels and an increased sense of empowerment for CF patients/carers within the medical appointment. Moreover, the designed check list is a new discursive template that facilitates a new patient-led approach to tackling and understanding the problem of flawed memory recall within the medical appointments.

This study contributes to knowledge research by providing a representative set of 10 design principles for the design of a check list for use by patients/carers to aid memory recall. The most novel of which is the unpacking of long-term declarative memory into its components, where the check list design actually maps to "*aid*" the memory type drawn upon by the patient/carer within the medical appointment. The result being more effective memory recall/information retrieval. In addition, two conceptual models emerged: 1) a model of information retrieval/memory recall within the *elicitation* phase of the medical appointment, augmenting our comprehension of this phase of the medical encounter for all stakeholders; and 2) a visualisation/model of reflection within the context of the ADR, which depicts the stages of exploration required to genuinely advance our understanding of a problem, dissecting viewpoints further, gaining deeper insights into phenomena, and developing our problem definitions.

As part of the ADR journey the check list (artefact) has been professionally produced in the form of a booklet, which has been adopted and distributed by CF Ireland to all CF patients/carers in Ireland. Furthermore, the NHS began distributing

the booklet in early 2020, starting with the Royal London Children's Hospital. Since then, it has gone to several countries across the world for review/evaluation by their relevant CF bodies.

Chapter One

1. Introduction

1.1. Introduction to the Study

After much debate (mostly with myself) I have decided to write this introduction in the first person. I appreciate that for many of you this is unexpected, but there is method behind this approach. I want to try and give you the reader some sense of who the researcher really is, and more importantly how I came about doing this PhD. I feel to do otherwise would betray me of telling my story and deny you the reader of what I hope is an interesting narrative.

1.2. Overview of the study

This chapter presents an introduction to the thesis. It endeavours to furnish the reader with a synopsis of each section of the research study, as this thesis is organised as a corpus of papers, with an introductory chapter and a discussion conclusion chapter. Again, taking a slightly different approach to what you may be accustomed to in a thesis, I intend on firstly describing the impacts of the research (Section 1.3) as they currently stand from a practice perspective, a form of "*Back to the future*" approach, if you will.

I follow this with the research setting and the motivation behind my enquiry (Section 1.4). This is followed by the research background (Section 1.5); here the concept of memory recall/information retrieval is developed, including the context from which I have viewed same. Additionally, I establish the scope of my memory

recall analysis, highlighting its relevance and importance. Next (Section 1.6) I outline my philosophy of science, ethical considerations, the research aim, research question and objectives. I also present a summary of the main research contributions to knowledge, having already highlighting the practical impacts earlier in Section 1.3. Thereafter, in Section 1.7, I define the composition of the research, incorporating the make-up of the thesis, a digest of each chapter and the rationale behind the inclusion of each paper. Finally, Section 1.8 brings the chapter to a conclusion.

1.3. Research Impact

It's 8pm and Mary, a 33-year-old, has just put her seven-year-old Cystic Fibrosis (CF) child Tommy to bed. She sits at the kitchen table and sighs; it has been a hard day. Tommy has been coughing a lot with a cold he picked up at school, and now has a medical appointment tomorrow afternoon at 3pm. Mary opens the check list booklet (Figure 1-1) that she received from the Cystic Fibrosis Ireland in early 2019. They said it was designed by an adult CF patient who, like herself, found recalling and capturing information within the appointment a difficult and stressful experience. A patient who wanted to answer the following; *How might we augment Cystic Fibrosis (CF) patient/carer memory recall/information retrieval within the elicitation phase and elucidation phase of the medical appointment?*

Mary works quickly filling out all the items highlighted in green text (following the check lists/artefacts guidelines/instructions) that she will need to remember within the appointment, such as his medications, symptoms etc. Moreover, she records all the questions that she and her husband, Joe, have for the doctor regarding Tommy's

current health status. Like any parent in Marys situation she worries, especially when Tommy is sick. She hears a muffled cough from upstairs, its 8.30pm; she passes the booklet to Joe for final approval. He gives her a thumbs up and closes the booklet, putting it on the hall table ready for the next day.

Figure 1-1 The Check List Booklet

They love the way the check list (Figure 1-2) is so cleverly structured and categorised according to the flow of the appointment. It makes preparation *before* an appointment so easy, and of course takes away the burden of trying to remember what needs to be remembered for the medical appointment. Mary goes upstairs to check on little Tommy, content in the knowledge that she is well prepared. It gives her a sense of empowerment and confidence previously absent when the check list was not in existence.

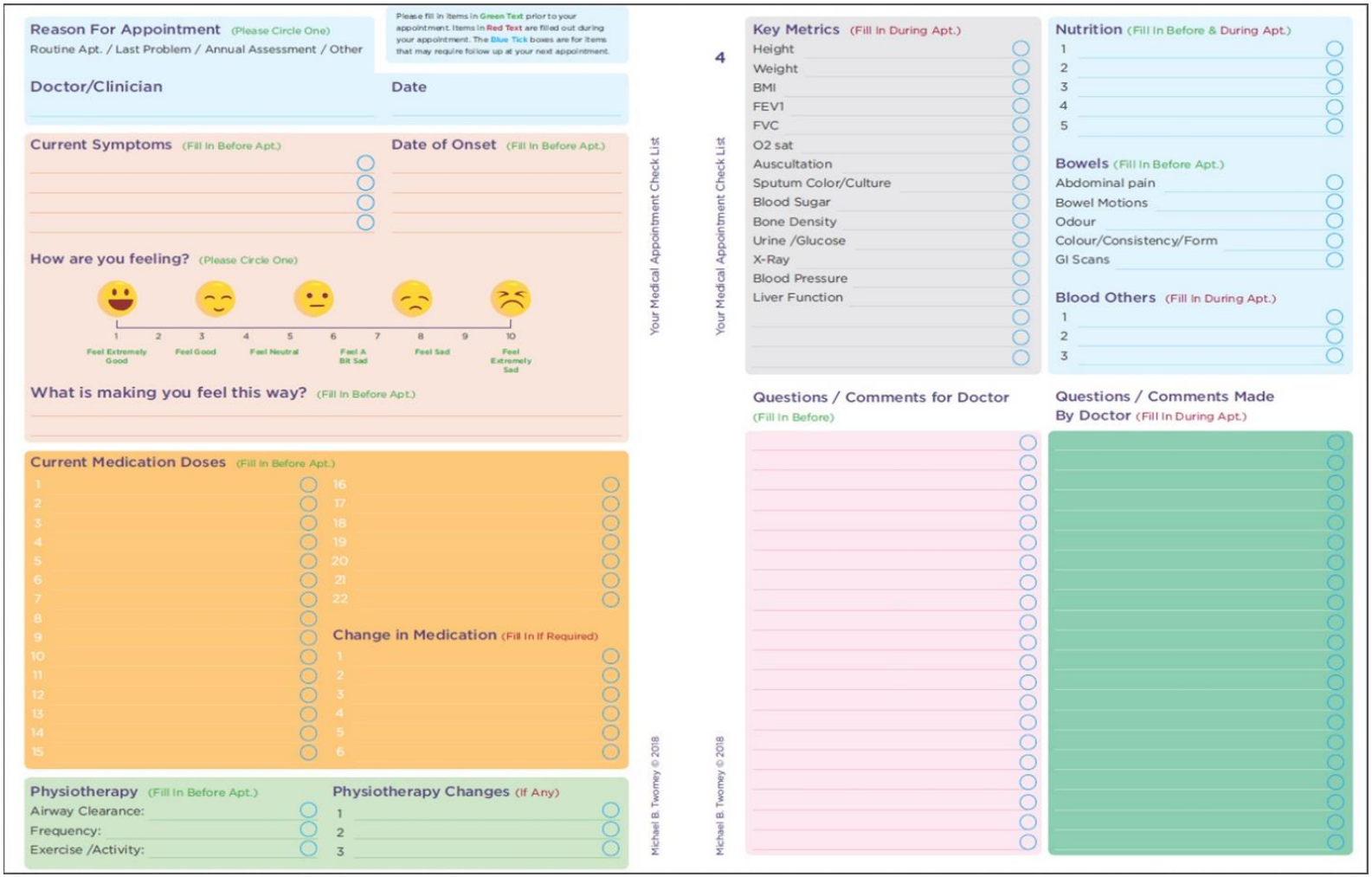


Figure 1-2 Booklet Form of Check List

It's 2.55pm the following day, and Tommy is playing with some toys in the waiting room of the clinic, while Mary is busy glancing over the check list once more. The check list facilitates a mental walkthrough of the medical appointment, refreshing Marys memory regarding Tommy's medical information. Moreover, it distracts Mary from the stress and anxiety that she feels bubbling within her as the appointment approaches. She squeezes the booklet, smiles at Tommy, and takes a deep breath, she feels ready. "*Tommy Brown please*" the receptionist calls out. It's time.

Within the appointment, Mary places the booklet squarely on her lap; she has always wondered why it sits there so well. She wonders was it designed so? The doctor asks *"So, Mrs Brown, how is Tommy doing? What medications is he currently on?"* For a brief moment Mary freezes, *"medications?"* she thinks, *"will I remember them all?"* Then her eyes drop quickly to the check list, "*no bother, sure it's all here in front of me"*, she thinks. With confidence, Mary rattles off all the medications. *"And what symptoms does Tommy currently have?"* the doctor inquires. Like a student seeking to impress her teacher, Mary lists Tommy's current symptoms without hesitation, and behaves in a similar manner to other questions raised regarding Tommy's medical history. The doctor seems somewhat amazed; she is still adjusting to the confident delivery of medical history information by Mary and other users of the check list booklet like her. She finds it extremely refreshing that the discourse between herself and the carer is now far less arduous, and indeed has become more natural, and that her job of diagnosis is made so much easier, as the information imparted by Mary is of such high-quality. Hence, she feels more confident in her ability to diagnose, and in the treatments she prescribes.

She is also delighted that Mary is recording the relevant information that should/needs to be captured within the medical appointment, all without impinging on the discourse between them. She knows that this will help Mary recall what has happened at the appointment later on and appreciates the impacts this has on adherence to treatments. Additionally, it allows Mary to recall with ease the events of the appointment for her husband Joe later on that evening, easing any tensions that may arise from an inability to recall information for an anxious spouse regarding a sick child.

As the appointment comes to a close, the doctor asks, "*anything else Mrs Brown?"* Mary ponders briefly and glances at the check list. Almost immediately the pink section in the check list captures her eye. *"Ah, yes Doctor",* she says. With that she lists the questions/concerns she has. One by one they are discussed, with answers given and recorded within the check list. A warmth envelopes Mary as she senses some of the burdens that she has being carrying slowly evaporate and ease. This is hugely important to Mary (and other carers) as it facilitates a relieving of psychological burdens, for her and her family.

The above experience I have endeavoured to encapsulate in Figure 1-3 (see Appendix Q for a representative data set), where I illustrate the various phases and processes that the patient/carer travels through, the sense of empowerment felt, the stress experienced, and the levels of information retrieval/memory recall effort required in each phase. Indeed, 81% of our research evaluation participants reported significant improvements in memory recall as a result of using the check list/artefact (Appendix D).

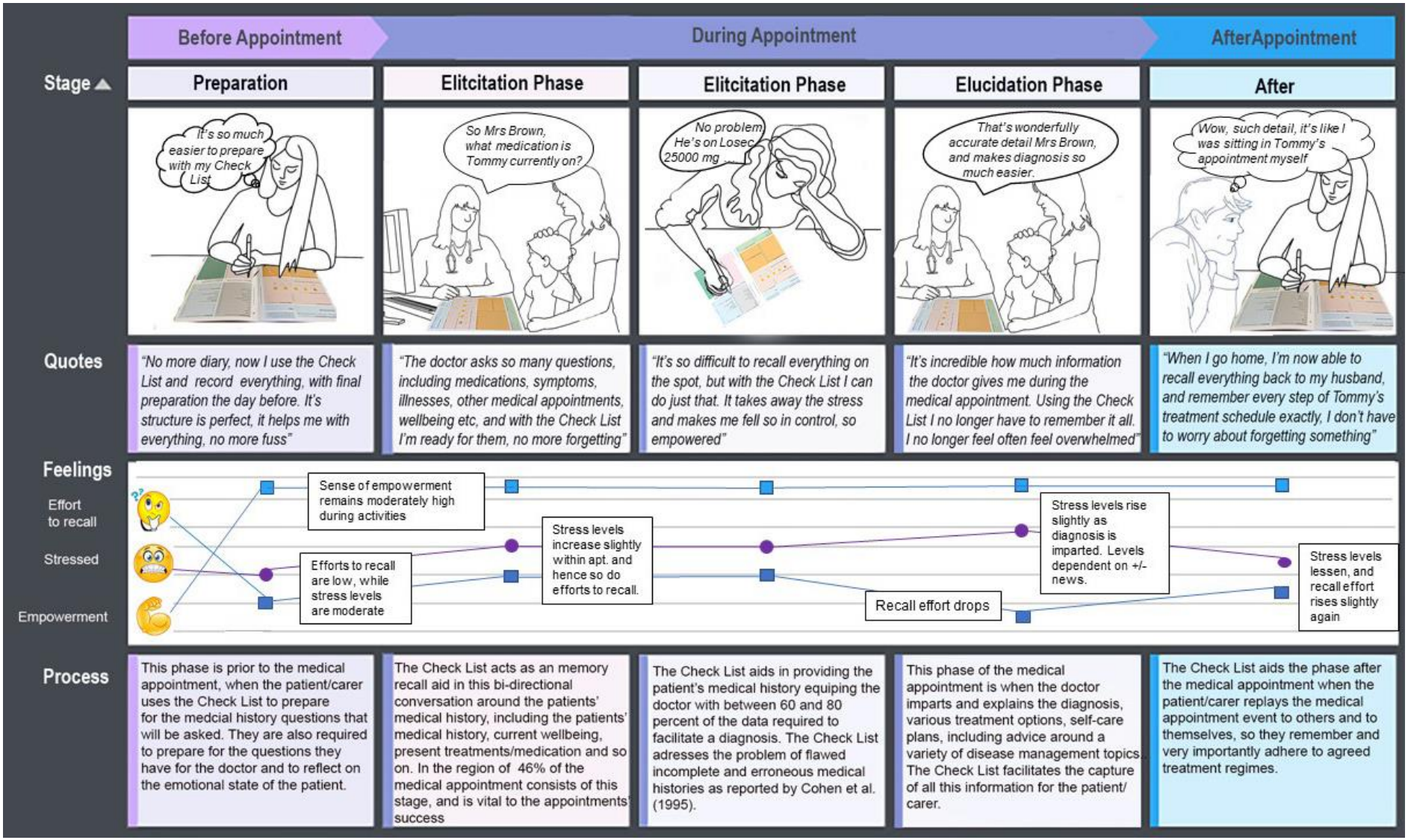


Figure 1-3 The Patient/Carer/Doctor Experience <u>Now</u>

Contrast this with Figure 1-4 (see Appendix Q for a representative data set), which portrays Mary's medical appointment experience before the check list existed, where efforts to recall were higher throughout the patient/carer journey, with increased levels of stress and lower feelings of empowerment.

This is interesting as stress effects our ability to remember (Appendix C - Paper 3) and also because of the significant associations between physical and mental health, where CF patients and their caregivers report *"elevated symptoms of depression and anxiety"* (Quinter et al., 2016, p.187). The increase in empowerment reported by patients/carers using the check list (Appendix A - Paper 1) is also noteworthy, as chronic patients/carers are known to engage in their illness more when they feel empowered to do so (Prigge et al., 2015). In addition, an increased sense of empowerment is known to improve the efficacy of treatments as it augments adherence to therapy regimes (ibid). Table 1-1 poignantly articulates the impacts of the check list on memory recall, stress, and empowerment of the patients/carers within the evaluation group of this Action Design Research (ADR) study. Perhaps not surprisingly, in 2019 the check list booklet was distributed to all CF patients/carers within Ireland by Cystic Fibrosis Ireland (my Irish Research Council Enterprise Partner).

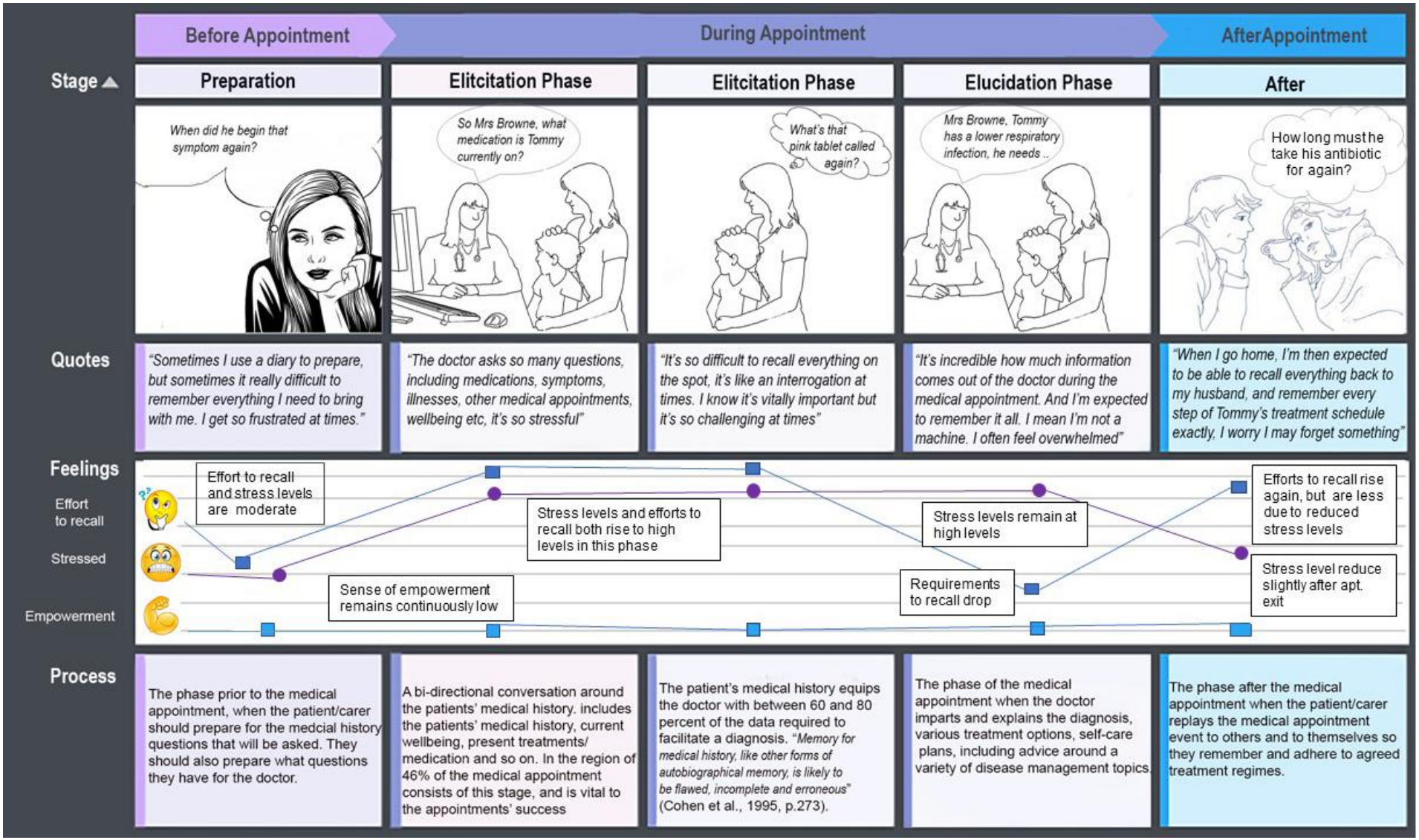


Figure 1-4 The Patient/Carer/Doctor Experience Before

Table 1-1 Check List impacts on CF patients/carers Memory Recall, Stress and Empowerment

Practical Impacts		
Stakeholder	**Comment**	**Impact Type**
CF Carer	*"For me the check list works so well as I now rely less on my own faulty memory. To be honest, having used it now for a few months I would be lost without it."*	Improved Memory Recall
CF Patient	*"Now when my doctor asks me questions regarding my medical history, I can just rattle off the answers. No more forgetting stuff, all thanks to this simple check list. And whenever I need to, I can go back to any appointment I want. It makes following my treatments so much easier. It so simple, but so effective."*	Improved Memory Recall
CF Patient	*"As a CF patient it's not easy. When I am at the appointment, I feel my heart racing, I am stressed about what the doctor might say about my health. The check list won't take all the stress away, but it sure does help a lot. More than I thought it would to be honest. It's amazing what a bit of paper can do."*	Reduced Stress
Carer of CF Child	*"With the check list for the first time I could really hear what the doctor was saying to me."*	Reduced Stress
Carer of CF Child	*"The check list may seem a small thing for some, but for me it was huge, I was so worried about my little girl, anything that helps reduce that stress is amazing. I don't think people should really judge unless they have walked in my shoes."*	Reduced Stress
CF Patient	*"I feel at long last that I have a real voice in the what happens with my body. Before I felt voiceless, unheard, not comfortable speaking about my concerns. Now I have the courage to speak my mind. I can't believe how good it feels."*	Increased Empowerment
CF Patient	"The doctor assumes that the treatment he recommends is ok with me, he never really asks me. But now when I come with the check list, he knows I mean business, that I am serious about my health, that I want to be heard, I want to have my say. I think it has really helped our relationship."	Increased Empowerment

Table 1-2 on the other hand, endeavours to capture the very positive reaction by CF patients and carers within Ireland to the check list booklet. From a personal perspective the feedback from CF patients/carers received was quite a significant moment in my PhD, not only was it deeply moving, it also engendered a profound sense of personal fulfilment. This is not to say that my ego has become in any way inflated, quite the contrary, I am all too aware of the work still to be done, so that my vision may eventually become a reality (discussed in Chapter 4 – Discussion & Conclusion).

Table 1-2 Reactions by CF patients/carers to the Check List booklet

Stakeholder	**Response to Check List Booklet**
	Comment
Carer of CF Child	*"We just wanted to say we received our medical appointment check list today and we just wanted to say THANK YOU so much, we love it and it's going to be incredibly handy for us, this is our son age 7 (photo included with email) and though it's just a book now to him, in a few years he'll know how great it is as well."*
Carer of CF Children	*"Congratulations on your check list book. I think it is fantastic and would have loved to have had something like it 30 years ago. I used to spend the week before appointments writing out my questions and hoping I wouldn't forget anything, and then having to remember to ask for results of the different tests."*
Carer of CF Teenager	*"We received 'Your Medical Appointment Check List' book from CF Ireland recently. I just wanted to say a very big thank you for making my daughter's life a little bit easier, she is getting ready for Adult Hospital in few years and finding the check list very helpful. She is well able to explain everything to her CF team because of your check list."*
CF Patient	*"It's fantastic, great job! We don't know how we survived without it."*
CF Patient	*"I got mine in the post today, it's brill."*
CF Patient	*"Great idea, it will save me so much time and energy!"*

Furthermore, the check list impacts have been confirmed/substantiated by the other major stakeholders within the medical appointment encounter, the clinicians (Table 1-3).

Table 1-3 Comments by CF clinicians on the Check List

Clinical Stakeholder	Practical Impacts Comment
Senior CF Clinical Psychologist	*"I have just come across your fantastic booklet ('Your Medical Appointment Check List'). I work with kids and adults with CF, and I have got quite a bit of feedback from teenagers; in particular that clinics can be repetitive and that it can be hard to remember the info. from all the different members of the team. I think the Likert scale with emojis is really good and is well received. Thank you!"*
CF Team	*"The CF team in OLHC have been very impressed with this check list and have asked us about it." - report from CF carer*
CF Clinician	*"I think the check list is a great idea and should really make a difference to medical appointments outcomes."*
CF Team	*"Although initially cautious of the check list, the Paediatric unit are now actively providing carers with their child's medical data to help them record their medical data in their check lists." - report from CF carer*
CEO CFI	*"Cystic Fibrosis Ireland warmly welcomes this excellent booklet of Check Lists for Cystic Fibrosis (CF). The aim of the booklet is to aid both patients and/or carers in the daily complex personal management of CF."*
CF Clinician	*"A great idea, it appears to include everything a patient would need for their appointments. It would help to give a really clear picture of the patients' current presentation."*
CF Clinician	*"It includes everything necessary for a patient's visit. Ensuring that nothing will be omitted at a visit, helping both the patient and the clinician."*
CF Clinician	*"A great resource to help patients to keep track of medication and symptoms. Appears to capture the essence of patient thinking when diagnosed with an overwhelming condition."*

Their endorsements led to several invites to present at conferences, for example, the *Engage - Hot Topics in Cystic Fibrosis* conference, held in October 2019 in the United Kingdom, and more recently at the *Irish National CF Clinical Meeting* held in January 2020. These assemblies are clinician-only events, where invites are only extended to impactful/novel medical topics of interest to the CF medical community.

Since then, the booklet (as a result of word of mouth) has been shipped to many countries for review/use by their relevant CF bodies (Figure 1-5). For example, in February 2020, hospitals within the NHS such as the Royal London Children's Hospital, in London, and Cambridge University Hospital, in Cambridge, started the distribution of the check list to all CF carers as an aid to memory recall within the medical appointment.

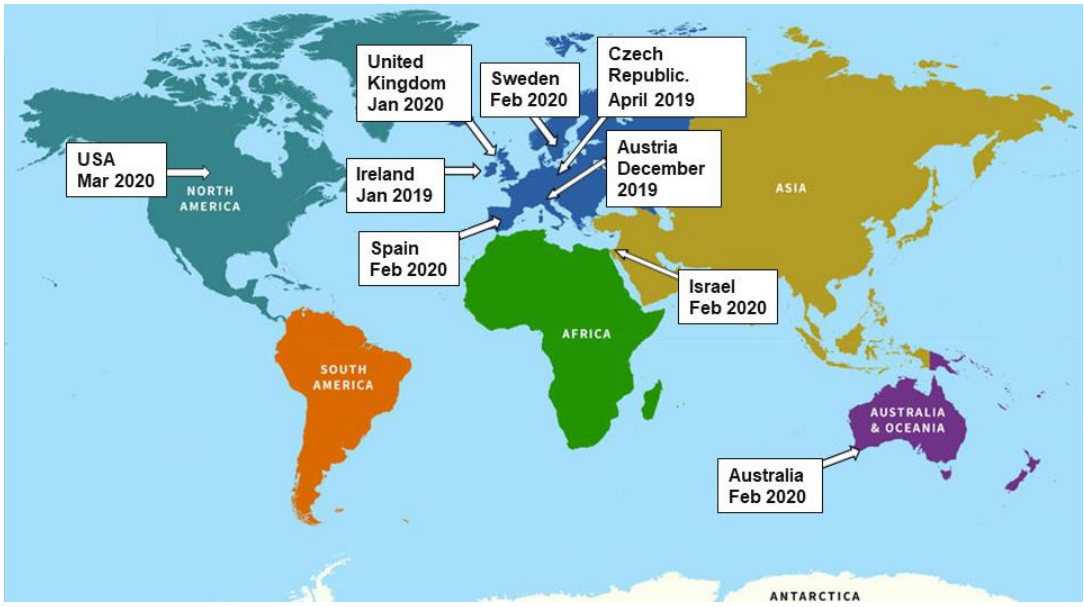


Figure 1-5 Where the Check List has travelled (09 April 2020)

So, one might well ask how did I get here? To be honest I often ask myself the same question, so in this thesis, I will narrate the story, and tell you how I got here. But

first let me try to convey to you the person behind the research, and the motivation for my journey.

1.4. The Researcher

So, who am I? To some I'm a researcher, to others a sibling, a son, to my wife I endeavour to be an adoring husband, and to my little boy of 10, I'm a father, someone to emulate. But in the context of this thesis, I am primarily the researcher, but also a Cystic Fibrosis (CF) patient who is trying to make a difference. So, what is CF? Put simply, CF is an inherited chronic disease, primarily affecting the lungs and digestive system. The primary defect is genetic in nature, involving the Cystic Fibrosis transmembrane conductance regulator (CFTR), which leads to an imbalance in the exchange of salt and water across the cell membrane, affecting all mucus generating organs, including the pancreas, sinuses, and reproductive system (Ratjen et al., 2015). Although CF is a multi-organ disease, the cycle of inflammation, primarily affecting the lungs, and coupled with infection and repeated pulmonary exacerbations, is a major cause of morbidity and mortality (Ratjen et al., 2015).

1.4.1. Research Motivation

The death of my dear sister Jane to CF in 1997 had a profound effect on me. I stood helpless, as she struggled to do what so many take for granted, the basic act of breathing. Her coughing spasms were horrendous, akin to caribou cry honks, after which she would rasp violently in an effort to expel the sputum which clogged her lungs. It was the first time that I watched a loved one breathe their last breath, watch

as their life support machine flatlined, and their very existence in this world faded away. The 29th July 1997 is a day that I will never forget.

Having CF is one thing but watching someone pass away with it leaves one at a psychological crossroads. Where do I go from here, I thought? How/what was I going to be following her death? Was I going to let myself become self-obsessed, letting this disease define who I was, or was I going to get busy living, appreciating life and doing my best to prevent this illness slaying me as well? After that harrowing day in July 1997, I opted to live my life with fervour. I owed it to my family, to myself. I chose to get on with it, no feeling sorry for myself, no time for wallowing. I knew my sister would expect nothing less from me.

Thankfully, I manage my CF quite well, and although I carry the burden of disease management and all that goes with it, relatively speaking I am in good health. That is not to say that I do not succumb to infections now and then, of course I do. This results in arduous breathing difficulties, occasionally coupled with the fear of death/a decline in my health status (the dark shadows as I call them), in tandem with augmented treatment routines (often painful and extremely tiring).

Living with CF and witnessing the hardship and devastation that it inflicts on patients and families has taught me to certainly value my good health. Statistically at 48 years old, I should probably be dead. And so, it would appear that I have been spared for some reason. I decided that my *raison d'etre* would be to give something back, to make the life of CF patients and carers a little easier. To make a difference to our experience of information retrieval/memory recall *within* the medical

appointment (visited next). This would be my destination, my focus, my passion, my calling.

As you can draw from my writings thus far, I am not one to conform to what many may consider the normal way of doing things. It was only last night that my wife and I discussed my returning to college at 44 years old to do a PhD on a fulltime basis, whilst also trying to solve a real-world problem. Without going into too much detail, we both concluded that I am a bit daft, but to be fair, once I set my mind on fixing something I go right after it (as one might expect from a pragmatist discussed in Section 1.6). Therefore, keeping in that spirit, in early 2017, I submitted an application to the *Irish Research Councils Enterprise Partnership Scheme.* In September 2017, to my surprise, and to my delight (and to the gratification of the family household financials), I was informed that I was successful in securing same.

Following this brief whistle stop tour, vis-à-vis me and the motivation behind my research, I am now, going to briefly visit the practice-inspired problem that I have already touched upon.

1.5. The Practice Inspired Problem

The primary rationale behind the medical appointment is to discover what ailment or health challenge that a patient shows evidence of within the medical appointment, or to "*make the diagnosis*" (Lazare, 1995). Constructing a diagnosis is akin to putting a jigsaw together, in that it's a cumulative decision-making process, fostered from fundamental data, where clinicians must constantly validate

their diagnostic judgments, by reflecting 'in practice' adjusting and considering their medical verdicts dynamically, in real time (Schön, 1983; Sibbald et al., 2015).

A significant amount of the data that a doctor requires in order to make a diagnosis comes from the patient or carer in the *elicitation* phase of the medical appointment. Here a bi-directional conversation around the patients' medical history, current well-being, present treatments/medication takes place (Sarkar et al., 2011). Indeed, in the region of 46% of the medical appointment consists of this stage, which is vital to the appointments' success, as 99 percent of patient day to day activities can occur in non-clinical environments (Martin et al., 2014). The patient's medical history that is pulled together in this stage of the appointment equips the doctor with between 60 and 80 percent of the data required to facilitate a diagnosis (Hampton et al., 1975; Sandler, 1980; Kassirer, 1983).

The upshot of inadequate information retrieval/memory recall in a medical appointment is reported to be significant regarding the quality of information conveyed to a doctor, his/her ability to arrive at a diagnosis, as well as treatment choices, all of which have a considerable bearing on the outcome of the patient (Cohen et al., 1995), and on the doctor's level of professional fulfilment/satisfaction (Schraa et al., 1982).

Unfortunately, over time the amount of information that a patient/carer is required to remember (their medical history) increases substantially, especially with a chronic condition/s where treatments and medical regimes all too often become increasing complex in nature (Martin et al., 2014). Moreover, as the quantity of material to be remembered grows, the percentage of accurately recalled data

deteriorates (McGuire, 1996). Hence, *"memory for medical history, like other forms of autobiographical memory, is likely to be flawed, incomplete and erroneous"* (Cohen et al., 1995, p.273). This is especially so in the elderly populace, who are found to be less capable at accurate information recollection (Watson, 2009), often due to a decline in cognitive function owing to the process of human ageing.

The temporal nature of medical appointments also poses a notable information retrieval/memory recall challenge for chronic patients/carers, where the frequency of clinical encounters becomes a significant factor; here the specifics of similar recurring appointments/events are seen to almost merge into one another (Rubin et al., 2015). In tandem with this, the very context of the medical appointment itself (occurring under severe time constraints) and of clinical environments in general, act as a source of stress to both patient and carers, making doctor-patient communication challenging (Ong et al., 1995). This is important as anxiety levels are reported to hinder information retrieval/memory recall (Kessels, 2003; Jansen, 2008; Safeer, 2005; Ley, 1979). Indeed, in many cases stress levels can increase simply by visiting a medical appointment, referred to as '*white coat syndrome'* (Martin et al., 2014). I will testify to this, as I experience it myself, where it manifests itself by elevations in my blood pressure readings and a real sense of unease. Additional factors affecting patients/carers information retrieval/memory recall include health literacy, education level, the form in which the information is delivered (oral or written), patient/carers belief's (Martin et al., 2014), emotional state, and forgetting. I go into depth on these memory recall challenges in my third paper (Appendix C).

The *elucidation* phase or the *explanatory* stage, is the phase of the medical appointment when the doctor imparts and explains the diagnosis, various treatment options, self-care plans, including advice around a variety of disease management topics (Martin et al., 2014). The information retrieval/memory recall of this phase is directly related to the patients'/carers' adherence and other self-managing actions, such as any alterations to clinical therapies (McPherson et al., 2008). In fact, studies confirm that patients/carers fail to recollect anywhere between 40 – 80 percent of the information communicated to them in this phase, almost instantaneously (Kessels, 2003). Not surprisingly, these failures in patient/carer memory recall (especially *after* the medical appointment) result in poor patient/carer adherence, moderated health outcomes and decreased patient/carer satisfaction (Schraa et al., 1982).

It is important to note that in the thesis I will distinguish between both phases where appropriate, or as required, otherwise, for more general commentary pertaining to both phases, I will use the wording "*within the medical appointment*". So now that you have an overview of the problem, it probably comes as no surprise why I, as patient myself, want to remedy the problem for CF patients/carers. But what of my proposed solution/artefact, why a check list?

1.5.1. Check Lists

In 2013, reports stated that between 200,000 to 400,000 patient deaths occur each year as a result of preventable medical errors (James, 2013), primarily due to deficient communication amongst stakeholders (Solet, 2005). In an attempt to address such shortcomings within the surgical environment Dr Atul Gawande set

his sights on the aviation industry to comprehend what they used to aid human endeavour in critical settings (including memory recall), situations that are not just complex but also highly capricious (Arriaga et al., 2013). There he discovered the use of the check list (used to fly a B-17 plane), defined by Federal Aviation Administration (2016, p.1) as *"a formal list used to identify, schedule, compare or verify a group of elements or . . . used as a visual or oral aid that enables the user to overcome the limitations of human memory"*. The surgical check list was born, now in operation globally it has reduced the number of surgical errors, leading to considerable increases in patient safety (WHO, 2010), helping to avert memory failures (Stock et al., 2015). According to Gawande (2010, page 45) *"under conditions of complexity, not only are check lists a help, they are required for success"*. Interestingly however, the WHO urges check list designers to adapt their check list to cater for the intended environment, an approach that has proven to be effective in fuelling teamwork and a perception of tenure (Leape, 2014).

1.6. Foreground and Research Approach

The purpose of this section is to clarify the philosophy of science, ethical considerations, research aim, and objectives that direct the research as well as the research method executed in order to achieve same. Next, an outline of the research outputs is visited, followed by the contributions made by the research to knowledge (having already covered those to practice in Section 1.3).

1.6.1. Philosophy of Science

It's a cold December morning in 2019, and the words of the eminent Canadian clinical psychologist and professor Paul TP Wong (2014) come to mind; "*Time spent in self-reflection is never wasted - it is an intimate date with yourself*". As I write this introduction to my thesis as part of my rite of passage into the research community, I am compelled once more to think back on my PhD journey and consider my philosophy of science. I will be the first to admit that when I first hoisted the sails of my research vessel, I never cared for or gave much thought about the philosophical groundings for my research.

However, as my PhD progressed, a maturity of mindset beckoned me to gather my thoughts regarding same. While my initial objective was solely to create change for CF patients/carers, I came to realise that change without knowledge creation is limiting in and of itself. Without the knowledge of those before me, I would not be sitting here, I would have no story to tell, and my research endeavour would be kindling on the bonfire of failure. Reflection was paramount to this endeavour; as American writer Margaret J. Wheatley (2002) said, *"Without reflection, we go blindly on our way, creating more unintended consequences, and failing to achieve anything useful"*.

I hope that my deliberations on my philosophy of science will not only be of contemporary relevance but will also go to defend my methodology and justify my research design. Owing to the fact that this is only a section of my thesis introduction, I will not be going into a long and detailed historical narrative on the philosophy of science. I intend to take you the reader on a brief journey, a journey

on what I think, are the now calm waters of my inner thoughts on the subject of philosophy of science as it pertains to me, and my research. Nevertheless, untangling the components for this challenge does require an initial background appreciation of the philosophy of science, and so let us begin.

Science is *"the systematic study of the nature and behaviour of the material and physical universe, based on observation, experiment, and measurement, and the formulation of laws to describe these facts in general terms"* (Collins, 2019). Whereas research is the activity or set of actions that reveals knowledge that can often be difficult to gain access to, that contributes to the understanding of a phenomenon (Kuhn, 1962; Lakatos, 1978). Put in another way, research is the gathering of data by means of experimentation and observation, whereas science is the construction and examination/testing of hypotheses by means of that data.

According to Popper (1959, p. 27), the scientific research process can be explained as follows: *"A scientist … puts forward statements, or systems of statements, and tests them step by step. In the field of the empirical sciences, more particularly, he constructs hypotheses, or systems of theories, and tests them against experience by observation and experiment"*.

While our methods need to be observable, testable, repeatable, and falsifiable through experimentation, what about the researchers' ontological perspective (their beliefs about reality and in turn about truth). Afterall, our ontological viewpoint rationalises our outlook on the world, expressing "*our more or less dumb sense of what life honestly and deeply means"* James (1960, p.17), affecting what we think we can know, the design of our research and influences the decisions we make and

the actions we take. And so, our ontological view, be it realist or relativist, is very important to understand, especially as it dictates our epistemological beliefs (the views we hold regarding knowledge and how we can come to know something). Here the realist holds an *etic* position where knowledge is objective and can be measured outside. In contrast, the relativist is *emic* and maintains that knowledge is subjective and depends on context inside and is interpreted. Paradigms are *"a philosophical and theoretical framework of a scientific school or discipline within which theories, laws, and generalizations and the experiments performed in support of them are formulated"* Merriam Webster Dictionary (2007). Kuhn (1970b, p. 175) defined them as *"the entire constellation of beliefs, values, techniques, and so on shared by the members of a given community*". These beliefs convey both ontological concerns and epistemological issues and underpin the selection of research methodologies. Some of the main IS paradigms are depicted in Table 1-4, however, I will not be visiting each paradigm in this section of my introduction as it would yield no value, and secondly, the undertaking would be too large and diverse to tackle.

I have included the table merely to illustrate the diverse nature of beliefs that a researcher may have, that directly influences a research approach, and of course to aid the reader in understanding my own philosophical beliefs which I outline next. Figure 1-6 strives to convey/depict my own philosophy of science and its impact on my research project. As one can see, I see myself as a pragmatist, but I have utilised an interpretivist lens in order to aid me in achieving my research aim. So how has this arisen one might ask?

Table 1-4 The main IS paradigms (adapted from Vaishnavi et al., 2019)

Research Perspective				
Basic Belief	**Positivist**	**Interpretivist**	**Design**	**Pragmatist**
Ontology	A single reality; knowable, probabilistic.	Multiple realities, socially constructed.	Multiple, contextually situated alternative world-states. Socio-technologically enabled.	Reality is the practical effects of ideas.
Epistemology	Objective; dispassionate. Detached observer of truth.	Subjective, i.e., values and knowledge emerge from the researcher-participant interaction.	Knowing through making - objectively constrained construction within a context. Iterative circumscription reveals meaning.	Any way of thinking/doing that leads to pragmatic solutions is useful.
Methodology	Observation; quantitative, statistical.	Participation; qualitative. Hermeneutical, dialectical.	Developmental. Measure artefactual impacts on the composite system.	Mixed methods, design-based research, action research.
Axiology	Truth: universal and beautiful; prediction.	Understanding: situated and description.	Control; creation; progress (i.e., improvement); understanding.	Goal Orientated.

Interpretive research aids a researcher to understand human thinking and the actions that are taken/performed in different contexts (i.e., social/organisational); it has the capacity to yield rich insights into phenomena (defined by Immanuel Kant (2007) as that which is conveyed via our senses, in contrast to noumena which are entities in themselves). Here Kant argues that all we can expect to ever access are phenomena, portraying the objective world as unreachable or beyond understanding. *"Observation is always selective … It needs a chosen object, a definite task, an interest, a point of view, a problem"* (Popper, 1989, p.46).

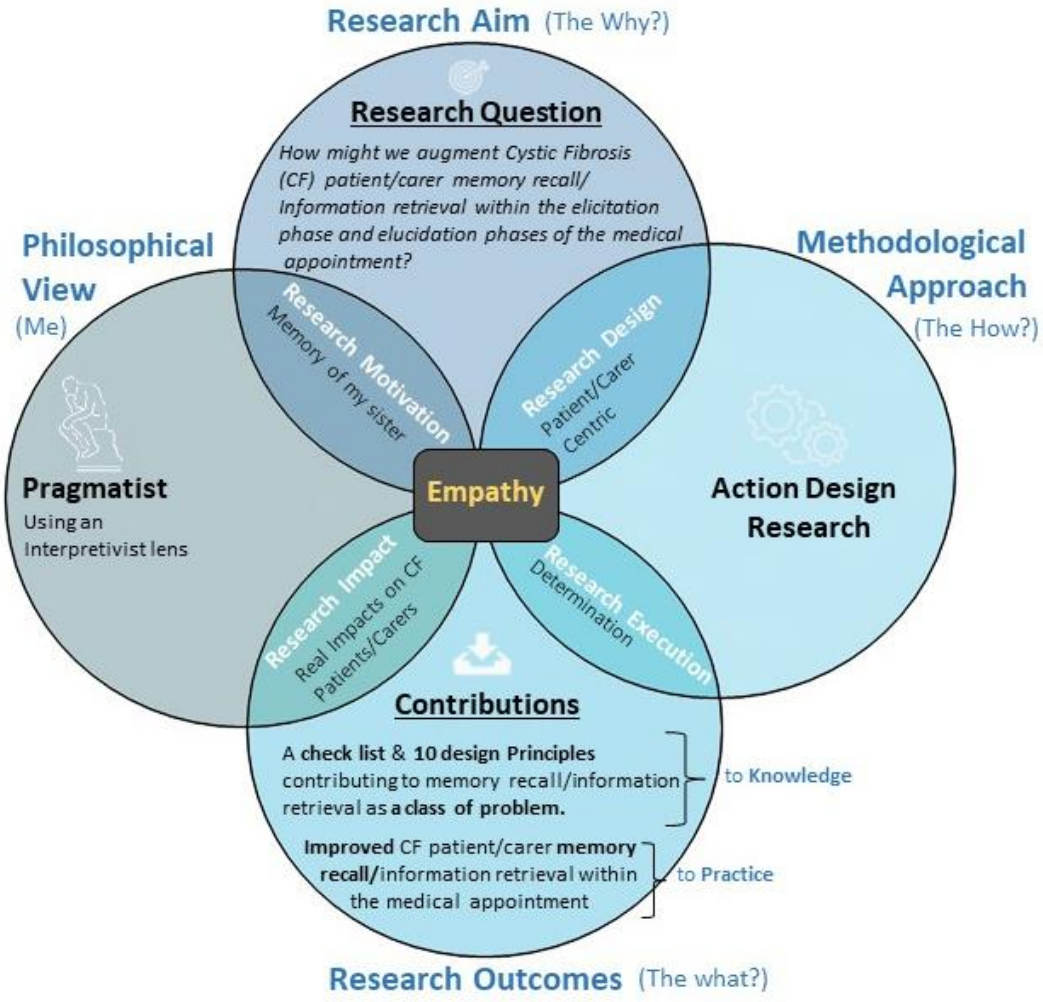


Figure 1-6 My Philosophy of Science and its Impact with my Research

In my study it was imperative to understand various stakeholders' realties, multiple realities if you will. Even though I am a CF patient, it became quite clear to me early in my research, that other CF patients and indeed CF carers experience the disease differently. I needed to comprehend their "*lived experience*", their ability to think and decide on particular actions. I also needed to understand the meaning that the check list (artefact) intervention was having for them. Hence the requirement for an interpretivist lens and the use of hermeneutics (the study of interpretation, or particularly the means of coming to understand (Lee, 1994; O'Raghallaigh, 2011).

On the other hand, when one lives with a condition that can kill you, you become a pragmatist very quickly, striving "*towards concreteness and adequacy, towards facts, towards action"* (James, 1978, p.31), to solve/remedy any problem that may hinder ones very survival. Identified as a paradigm by MacKenzie and Knipe (2006), pragmatists believe that research methods should be aligned with the desired practical outcomes (Peirce, 1958). *"To a pragmatist, the mandate of science is not to find truth or reality, the existence of which are perpetually in dispute, but to facilitate human problem-solving"* (Powell, 2001, p. 884). And so, my mission was also to create real value through an artefact, by ameliorating the problem of poor memory recall within the medical appointments of CF patients/carers, whilst also contributing to knowledge so that others may learn from my endeavours, and hopefully create solutions of their own for patients/carers of other chronic conditions.

Yet, in order to accomplish this and design an effective impactful artefact/s, I would need to advance my understanding of people's heterogenous situations, "*to follow*

either logic or the senses, and to count the humblest and most personal experiences" (James, 1904, p.12). And so, I have placed empathy at the focal point of Figure 1-6. Writer Mohsin Hamid defines empathy as "*finding echoes of another person in yourself*" (Leyshon, 2012), while English Novelist George Eliot deems it to be "*the highest form of knowledge"* (Haussamen, 2016). I believe that it was imperative to include and build empathy for CF patients/carers diverse situations in order to design the most effective artefact possible. Of course, to do this meant selecting an appropriate methodology (Section 1.6.4), in order to deliver real world impacts, contributions to practice, in tandem with outputs to knowledge.

1.6.2. Ethical Considerations

At its simplest, ethics can be defined as a system of moral principles. Etymologically speaking, the concept originated from the Greek word ethos, meaning custom or convention, or the spirit of community. which can mean custom, habit, character or disposition. According to the former Associate Justice of the Supreme Court of the United States Potter Stewart, "*Ethics is knowing the difference between what you have a right to do and what is right to do".*

Despite the fact that much of the discussion on ethics within IS literature concerns the epistemological and ontological view of the researcher, there has also been an acceptance that ethical attention ought to be built-in into research design (Stahl et al., 2014; Freidman et al., 2008). Where the examination of ethical concerns related with the design of technological artefacts, and the consequences of their subsequent use, it is paramount to the responsible evolution of IS research (cf. Mingers and Walsham, 2010; Davison et al., 2001; Davison, 2000). Notwithstanding, the

challenges that may arise in gauging the costs/impacts to individuals, organisations, and society (Stahl, Timmermans and Mittelstadt, 2016), there is still an onus on the researcher/s to make sure ethical purpose, that is to say, respecting fundamental rights, principles and values (cf. Friedman, Kahn and Borning, 2008). This is especially true, when seeking the involvement of patients (Morse and Field, 1996; Haber,2002). And so, in this section I will examine the ethical issues that I considered before & during my research.

Even though much has been written apropos the merits of ADR, there continues to be a shortage of guidelines for researchers who aspire to encompass ethical considerations into artefact design (cf. Chatterjee at al., 2009). However, following consultation of medical research literature, I found Hammick's (1996) research ethics wheel (REW) (Figure 1-7) to be appropriate for a comprehensive examination of the ethical considerations underpinning my study, and have encapsulated same into Table 1-5 to Table 1-8.

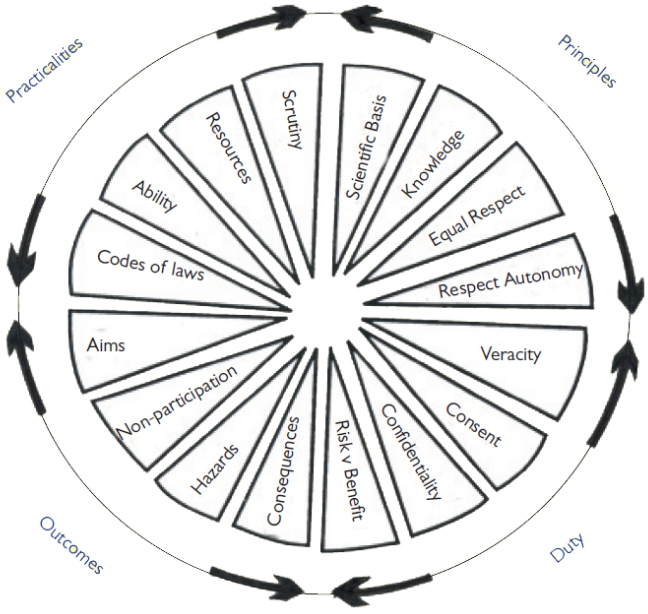


Figure 1-7 The research ethics wheel (Hammick, 1996)

Table 1-5 starts with how I contended with the four ethical principles, including my aim to contribute to knowledge whilst also addressing a real-world problem (practical contribution) using ADR (a scientific design method). Here too I refer to the principle of mutual respect, in this study this also included respect for various cultural/demographic groups, as patients/carers with CF come from many walks of life. It was important that this also acknowledged the influence of individual patient preferences, beliefs and an individual's illness experience (Pachter, 1994), as I mention a number of times in the thesis, just because I have CF does not mean I experience the illness the same as others.

The principle of autonomy centred around questions relating to consent. How can I best communicate what they are consenting to? What is the process for withdrawing from the study? Have all patients/carers consented? In considering beneficence (meaning to do good) and non-maleficence (meaning not to do harm), I was adamant that there would be full transparency, as advised by Turilli and Floridi (2009) who maintain the importance of same as a pro-ethical requirement that can damage, or facilitate, other ethical practices and principles. Moreover, no patient/carer would be coerced to partake in the study in any way, this despite the fact that I needed to enrol as many CF patients and carers as possible to conduct my evaluations. In other words, CF patients/carers would not be used as a means to an end. Respecting dissimilar points of view is crucial to the practice of autonomy (Martin et al., 2014). In fact, some patients/carers did not enrol as they didn't have the time, due to their current burden of disease management, whilst other simply were physical not well enough to do so.

Table 1-5 Ethical Principles

	Ethical Issue	Definition	Application in this study
Principles	Scientific basis	In accordance with the Declaration of Helsinki (World Medical Assembly, 1989), research ought to '*conform to generally accepted scientific principles.*	This study used Action Design Research (Sein et al., 2011) as its research approach. ADR is well citied as a scientific approach within Information Systems research.
	Knowledge	*"A study should only be conducted if it aims to increase the body of knowledge for a particular discipline"* (Whiting & Vickers, 2010).	Table 4-2 outlines our research contributions to both knowledge and practice.
	Equal respect	In research everyone should receive equal respect and treatment (Beauchamp and Childress, 2001; Burns and Grove, 2005).	As a patient myself, this was very important, and so, I sought to build genuine relationships, typified by a deep sense of trust, with full disclosure, mutual benefit and respect.
	Respect autonomy	Self-rule that is free from both controlling interference by others and from limitations, such as inadequate understanding, that prevent meaningful choice (Varelius, 2006).	Participants were able to decide of their own free will whether or not to become involved in this research. In this study, patients were initially approached by the CFI, who explained what the research was about, its aim, and what was involved. Written information was also provided to them regarding same. If the patient/carer then wished to participate, they contacted me directly via email.

Questions regarding anonymity and confidentiality (Table 1-6) are often problematic in ADR and practitioner research, especially in qualitative enquiries that are emergent in nature and entail assembling comparatively unstructured data in naturalistic settings. Consideration apropos same are vital, as the potency of qualitative research methods often rests in the informality of the communication, where confidentiality allows *"people to talk in confidence"* (Piper and Simons, 2005, p.57). And so, I took appropriate measures designed to ensure that all personal data was safe from unforeseen, unintended, or malevolent use (European Commission, 2013), for example all data was encrypted using Microsoft BitLocker Encryption Technology. BitLocker Drive Encryption is a data protection feature that integrates with the operating system and addresses the threats of data theft or exposure from lost, stolen, or inappropriately decommissioned computers. Data on a device cannot be accessed without the Bit locker encryption key. Anonymisation on the other hand, was ensured through the pseudonymisation and or generalisation.

According to Cennydd Bowles, "*design is applied ethics*" (2018, p.4), and *"while deontologists focus on duty, utilitarians look only at consequences,"* (Bowles, 2018, pp.52–125). Thus, in terms of ethical probity, one must also consider the risk versus benefit of a research endeavour, and indeed the outcomes/consequences of engaging in certain research topics, which can be more or less "*sensitive*" (Renzetti & Lee, 1993), where certain categories of participants such as patients/carers maybe more exposed to certain risk than others. This is especially important in qualitative research, which can by its very nature be more capable of intruding into people's private lives than quantitative work.

Table 1-6 Ethical Duty

	Ethical Issue	Definition	Application in this study
Duty	Veracity and Consent	Veracity is the quality of being true, honest, or accurate (Cambridge Dictionary, 2020). *"The process of agreeing to take part in a study based on access to all relevant and easily digestible information about what participation means, in particular, in terms of harms and benefits"* (Parahoo, 2006, p.469).	CF patients/carers were provided with all the facts about the study, in order for them to provide informed consent. Moreover, they were then asked to sign an informed consent document prior to engaging in the study.
	Confidentiality	"*Assurance given by researchers that data collected from participants will not be revealed to others who are not connected with the study*." (Parahoo, 2006, p.466)	Parkes (2006) states that any information that links the identity of a participant should be changed (in order to anonymise same), hence, pseudonyms or codes were used in the writing of this thesis, including all publications. Additionally, to ensure confidentiality, my supervisors and I were the only ones aware of this source of this information. Furthermore, all data was encrypted and securely stored.
	Risk versus benefit	The researcher's responsibility to make sure that the participants are not connected to a study that will either benefit them or anyone else in an unethically manner (Whiting & Vickers, 2010). Furthermore, it seeks to safeguard the participants from any preventable harm or discomfort. (Ibid)	Working with the CFI and CF Clinicians ensured due care was taken to circumvent any potential harm to participants, as there was particular concern vis-à-vis conducting interviews on such an emotive subject, in that it may cause upset/distress. Furthermore, as a researcher/CF patient myself, I also had to be mindful of the interviews possible toll on myself. Hence, appropriate processes/failsafe's were put in place, should such an event arise during the project.

Hence, I gave further consideration (together with my research partner, the CFI and clinicians) to same by asking who could be harmed by this study (Table 1-7) and how? Moreover, how may any potential harm be avoided/minimised? And so, to prepare for any incidents that may arise during the various phases of the research process, a plan was carefully put in place. For example, should any of the participants get distressed, the recorder would be stopped and they will be asked if they wish to continue. Additionally, should they require support, I was to pass on the relevant details of a healthcare professional working with Cystic Fibrosis Ireland (CFI). Not surprisingly, the CFI has considerable experience in this area and have direct lines of communications/access with the relevant HSE bodies/departments and clinicians should they require them at any stage for the CF community.

Indeed, boundaries may become even more blurred when the academic researcher is also a patient, in this case a CF patient/researcher investigating the development of an artefact to aid memory recall/information retrieval by CF patients/carers within the medical appointment. As I state in Chapter 2, I sometimes found my research quite challenging from an emotional perspective, especially whilst conducting interviews, where I came to hear their stories, tales of toil and loss, intertwined with resilience and fortitude. Indeed, as a patient/researcher myself, I was also advised (by the CFI and others) that I be mindful of my own disposition, and to be cognisant of any effects that the research may take on myself. However, so was my determination to succeed in my research (if not me who would solve this problem?), that I quickly learnt coping mechanisms that worked for me, allowing me to compartmentalise my thoughts and feelings when and as required. Owing to

the constraints of this section, I will not delve into same now, but I do intend on writing a paper on this subject in the very near future.

Table 1-7 Ethical outcomes

	Ethical Issue	Definition	Application in this study
Outcomes	Consequences	As researchers we must be aware of the possible unintended consequences. Referred to by American sociologist Robert K. Merton as "*the outcomes of a purposeful action that are not intended or foreseen"*.	In the case of any participants becoming distressed or unduly upset as a result of an interview, relevant confidential CFI details were given to them. Moreover, as advised by Adobe's Vice President of Design Jamie Myrold I conducted a number of workshops to ascertain if there were any ways in which the check list could be used nefariously (Barrett, 2019).
	Hazards	As already mentioned above under "*risk versus benefit*", the researcher undoubtedly has a responsibility to ensure that the research does not involve any unnecessary risk.	This study did not engage in any changes to treatments or other medical interventions, hence, there were no further concerns besides those previously mentioned.
	Non-participation	It is vital that participants feel comfortable refusing to engage in a study, and that the matter of non-participation or resigning from a study is dealt with appropriately and without judgement (Hammick, 1996).	It was made very clear at the very start of the study (in the consent form), and during same, that any participant could disengage from the project at any time, and without offering any reason.
	Aims	The aims of any research project should be realistic and achievable; failure to do so could be perceived as being unethical, as it may offer false hope etc to those in a potentially vulnerable disposition.	It was made clear from day one that I sought to answer the following: *"How might we augment Cystic Fibrosis (CF) patient/carer memory recall/ information retrieval within the elicitation phase and elucidation phase of the medical appointment"*?

When conceiving a new tool, a designer designs for users, based on their concerns, culture, physical and emotional needs. In this instance I was also the user, a CF patient with 48 years' experience living with the condition, a patient who had attended at least 192 medical appointments. Was this an advantage yes, where there any downsides? Yes of course, the concern regarding bias in research remains in the background of all research. Researcher bias occurs when the researcher has individual biases or a priori beliefs that he/she is incapable of remedying (Onwuegbuzie, 2007). As stated by innovation designer Ferdi van Heerden *"all designers inevitably stamp a part of their personality"* onto their work (Scherling & De Rosa, p.18). A frequent threat to legitimation in research, researcher bias may subconsciously affect any area of a study, from data collection to data analysis. In the case of my research, I had to be cognisant of bias on a number of levels, for instance as a CF patient I had to be careful that I was not influencing participants unduly, in such a way that their behaviours, beliefs, or experiences were affected. This was managed/circumvented via the other stakeholders involved (CFI, clinicians and of course my supervisors) who acted as a sound board to my research design/approach.

My evaluations were conducted via semi-structure interviews, and so it was vital that my questions in no way led the participants, and so, rather than asking *"what did you like/dislike about the check list"* I would ask questions like *"describe the last time you used the check list in your medical appointment?" "How do you feel when you used the check list?"*

Another possible bias that occurs in research is confirmation bias. One could argue that my desire for success was such that I might discard those who challenged my viewpoints. In counter to this, pretotyping was used to gauge user interest (prior to any digital solution) whilst refraining from *"falling in love"* with any solution/s. Moreover, validity vis-à-vis the robustness of the research is supported by the external endorsement of the check list (beyond the 18 evaluation participants) including the CF community in Ireland, CF Clinicians (including those outside of Ireland i.e., the NHS). Following international requests to see the check list booklet, from a number of countries (Figure 1-5), I hope to also address any geographical/cultural diversity bias that may exist. Again, this is an important area of future research which I feel is worthy of further exploration.

As I state a number of times in the thesis, in the beginning I unconsciously affected by *"implicit bias"* (a type of stereotyping), in the sense that I thought that I knew how all CF patients were affected by CF, because I was a CF patient with so much knowledge and experience of the condition. After my first interview this notion was quickly dashed. Nothing could be further from the truth; my eyes were opened. I think in some ways it was probably one of my greatest learnings on the subject of human bias. Immediately it became clear that I really needed to spend time comprehending CF patients/carers *"lived experiences"* via a number of design thinking tools, i.e., empathy maps (Appendix F) and personas (Appendix G).

Finally, I briefly look at ethical practicalities (Table 1-8), it is of course fitting that a researcher informs themselves as to which type of ethical approval they need to apply for within their institution.

Table 1-8 Ethical Practicalities

	Ethical Issue	Definition	Application in this study
Practicalities	Codes of laws	Researchers must keep to codes of practice, legal obligations and regulations (Hammick, 1996)	The University College Cork Social Research and Ethics Committee has reviewed and approved the submission for this study (application log 2017-090). And the study followed the rules and regulations as laid out by the Social Research and Ethics Committee.
	Ability	It is essential that the researcher is appropriately qualified and has the right skillset/ ability to undertake the study (Hammick, 1996).	I undertook this study as my PhD, having already completed an MSc in Data Business. The research was under the direct supervision of my supervisors, in tandem with the CFI as research partner and a number of CF clinicians.
	Resources	Consideration must be given to resources required for the research (Whiting & Vickers, 2010).	I opted to do this study on a full-time basis, but sought grant support from The Irish Research Council and the CFI (Enterprise partner) in order to ensure the relevant resources were available. Moreover, as a patient myself, I was very aware of the burden of disease management, and hence the time demands of participants. This aspect should not be underestimated—the sense of responsibility towards the participants is very powerful (Whiting & Vickers, 2010, p.66).
	Scrutiny	It is vital that a study is scrutinised by independent sources; including the relevant ethics and research governance committees (Whiting & Vickers, 2010). Additionally, it is important that all findings are presented in an unbiased way, so enabling the sharing of knowledge (Hammick, 1996).	As mentioned above, the University College Cork Social Research and Ethics Committee has reviewed and approved the submission for this study (application log 2017-090). Additionally, each publication from the research has been peer reviewed prior to publication.

This research in this study was directed on the wellbeing (in terms of augmented memory recall/information retrieval, reducing stress, and increasing patient/carer empowerment) of CF patients/carers, and so I applied to the University College Cork Social Research and Ethics Committee for ethical approval, with approval granted in 2017. Having just completed a Masters in Data Business, I was appropriately qualified and supervised to engage in this project. Moreover, I had secured funding/backing from the Irish Resource Council and CF Ireland, which ensured that I/my research was suitably resourced/supported.

As one might expect all publications/outputs from this research (Section 1.7) were reported in an unbiased manner and subject to a blind peer review process, facilitating appropriate dissemination of knowledge.

1.6.3. Research Aim and Objectives

The ability of the patient/carer to recall what occurred (or was imparted by the doctor) *within* the *elucidation*/*explanatory* phase of a medical appointment is of course important, as it impacts patient/carer adherence to treatments etc (Martin et al., 2014). Although some research has been done on this phase, especially in relation to adherence to treatments etc, much less has been done on the *elicitation* phase (Cohen et al., 1995). In simple terms, a patient's medical history data acquired from the patient/carer in the *elicitation* phase of the medial appointment is crucial to the facilitation of a correct diagnosis by a doctor (Ibid). And so, the ability of a patient/carer to accurately recall or retrieve this data from memory becomes vital to the success of this diagnostic process (Cohen et al., 1995).

But researchers/clinicians/practice have heretofore been unable to adequately support patients/carers in their memory recall endeavours *within* either phase of the medical appointment, especially the *elicitation* phase. Moreover, they have failed to propose a tailored approach that takes into account the unique requirements of patients/carers with a specific chronic condition/s, notably Cystic Fibrosis. Taking this patient/carer cohort within the Republic of Ireland, the research aim of this study is, as previously stated, to answer the following question:

Research Aim: *How might we augment Cystic Fibrosis (CF) patient/carer memory recall/ information retrieval within the elicitation phase and elucidation phase of the medical appointment?*

I visit both phases in the study, nevertheless, my focus will be more on the *elicitation* phase (due to its importance in the diagnostic process), but this is not to belittle the significance of the *elucidation* phase of the medical appointment. The research objectives that are central to achieving the research aim are identified and described in Table 1-9.

Table 1-9 Research Objectives Guiding This Study

Demonstrated in paper	Objective	Question Type	Question	Complete
Papers 1-5	**1**	**Why?**	Explain why memory recall/information retrieval is so important within the context of the medical appointment?	**Y**
Paper 1, Paper 4, Paper 5	**2**	**How?**	Rationalise the research paradigm, methods, and techniques appropriate to the research objective.	**Y**
Paper 1	**3**	**What?**	Develop an artefact in the form of a check list that aids CF patients/carers memory recall within the medical appointment environment.	**Y**

1.6.4. Research Method in Brief

In his influential opus, The Sciences of the Artificial, Simon (1996 p.130) maintains that "[*e]veryone designs who devises courses of action aimed at changing existing situations into preferred ones"*. (ibid p.12). He appeals for "… *a science of design – intellectually tough, analytic, partly formalizable, partly empirical and teachable*" (ibid p.113). Having outlined my philosophy of science earlier, it will probably come as no surprise that my research paradigm is a design research. Design research has, like other paradigms, spawned into different types with a variety of names (Design Science (DS), Design Science Research (DSR), and Action Design Research (ADR)), but ultimately, they all utilise the same four step process as outlined in Table 1-10 (Nagle et al., 2016).

Table 1-10 Design Research has several flavours and labels (Nagle et al., 2016)

Research Approach	Design Guidelines (Hevner et al., 2004)	Design Science Process (Peffers et al., 2007)	Action Design Research Process (Sein et al., 2011)
Problem Definition	Problem Relevance	Problem Motivation and Relevance	Problem Formulation
		Objectives of Solution	
Design and Build	Design as an artefact	Design and Development	Building, Intervention, and Evaluation
	Design as a Search Process		
Evaluation	Design Evaluation	Demonstration	
	Research Rigor	Evaluation	
Contributions	Research Contributions	Communication	Reflecting and Learning
	Communication of Research		Formalization of Learning

These "*different flavours and labels*" (Ibid, p.3) for design research are used interchangeable throughout the thesis, however I predominately refer to ADR, owing to its focus on "*generating prescriptive design knowledge through building and evaluating ensemble IT artifacts in an organizational setting"* (Sein et al., 2011, p.4).

Design science is a '*problem solving'* paradigm (Niehaves, 2007) and seeks '*utility'* (March and Smith, 1995). Moreover, it is appropriate when research aims to create artefacts that address so-called *'wicked problems'* (Hevner et al., 2004). March and Smith (1995) see the purposeful building and the ensuing evaluation of artefacts as two of the most important tasks in design research. Afterall, the artefacts have to be evaluated in order to conclude if any progress has been made. Hence, as a pragmatist, choosing design research as my methodology made sense, given its suitability to the creation and evaluation of entities that serve human purposes (Simon, 1996). However, in order to do so, and avoid poorly designed artefacts, or artefacts that had any adverse side-effects, artefacts were evaluated within context, as recommended by March and Smith (1995). This approach is also advocated by Wieringa (2010), who argues that "[*t]he only way to produce conditions of practice is to move to practice*".

My problem formulation/exploration started with my own experience of the medical appointment (48 years), in tandem with a survey of 305 patients/carers (DS1 in Table 1-11), followed by interviews of 18 CF patient/carers artefact evaluators (DS2 Table 1-11). My artefact evaluation involved naturalistic evaluation, comprising of subjective ex-post discussions pertaining to the use of

instantiations of the check list artefact by real CF patients/carers (DS3 Table 1-11), within the natural environment of their medical appointments. This evaluation was complemented with clinician appraisal (DS4 Table 1-11), where 7 clinicians were interviewed, and a further 12 asked for a *"request for comment",* on the check list regarding the check lists' design, experience of its use within their clinics (where applicable), and any concerns regarding its intended use. I explain these concurrent evaluation activities through an interpretive lens (Figure 1-8), focusing on interview narratives using four qualitative metrics - completeness, usability, robustness and impact (Appendix D) that shaped our/my sense-making activities (Klein & Myers, 1999) in workshops (combining this evaluation data with workshop data DS 5 (Table 1-11), and literature DS6 (Table 1-11)). It is important to understand that the data sets DS1 to DS6 (Table 1-11) are the data sets that were generated and used throughout my research.

Table 1-11 Data sets in the study

Data Sets			
Data Set	**Description**	**Date**	**ADR Stage**
DS1	**Survey:** A list of questions aimed at extracting specific data vis-à-vis patients/parents' thoughts, opinions, and feelings regarding their data experiences within the medical appointment, specifically within the *elicitation* phase and *elucidation* phase. 305 respiratory patients/parents were surveyed using Survey Monkey. This sample selection allows one to take a broad view of the findings from the sample to the population.	15 Apr. 2015	Problem Formulation
DS2	**Interviews - Before Check list use:** 18 Patient/carers user evaluators - 27 hours of patient/carer interviews. Semi-structured interviews were conducted with each patient/carer evaluator, in which questions around their experiences (prior to using the check list) within the medical appointment were posed (specifically within the *elicitation* phase and *elucidation* phase. First, the interview approach was considered, designed and planned, determining the approach (semi-structured), the research questions to be posed, and any practical, conceptual and ethical external factors to consider. For example; patients were interviewed using telephone/conference call technology in order to avoid any cross-contamination issues, whilst carers were interviewed face to face. Second, the interviews themselves were conducted, and their results were subsequently transcribed. Third, the results of the interviews were analysed and interpreted and reported.	June 2016 to Sept. 2016	Problem Formulation
DS3	**Interviews - After Check list use:** Interviews conducted as above with each evaluator (18 in total), for each iteration (4 Iterations in total) of the check list. This encompassed 158 hours of interviews, with a mixed framework of general themes and pre-established questions asked in order to obtain information and narrative information regarding their experience, opinions of using the check list within the *elicitation* phase and *elucidation* phase of medical appointment.	Sept. 2016 to Jan. 2019	Evaluation

Table 1-11 continued ….

Data Sets			
Data Set	**Description**	**Date**	**ADR Stage**
DS4	**Clinician - Feedback:** Experts in a given area can help provide a measure of credibility to a study. I sought to generate the essential feedback from clinicians (via email - *"requests for comment"* and interviews) regarding the check lists' design, and their view ref same including the ramifications of its intended use. I began by defining the problem in some detail, and explained how the check list solution ameliorated same. By doing this I hoped to gain feedback apropos risks/unintended side effects (as well as advice as to how they might be addressed etc), perceived benefits, observations of use within their clinics, design improvements/suggestions, and of course to gain clinician *"buy in"*. - 7 clinicians interviewed. - 12 clinicians respond to *"requests for comment"* via email.	Sept. 2016 to Dec. 2018	Evaluation
DS5	**Workshops:** Included 4 design evaluators – 20 hours of workshops - involving brainstorming, sketching out ideas, Design Thinking tools (from personas (Appendix G) to empathy maps (Appendix F), and journey maps (Appendix H & I)). In tandem with sense-making activities following evaluation feedback, practical experience and due consideration of literature.	September 2016 to December 2018	Build/ Intervention/Evaluation/ Reflection & Learning
DS6	**Literature:** Encompassing the following: ADR methodology, design thinking, problem formulation, memory and cognition, check list design, colour and cognition, patient psychology/behaviour, interviewing, open coding, diagnosis/decision making etc.	October 2014 - December 2020	All stages

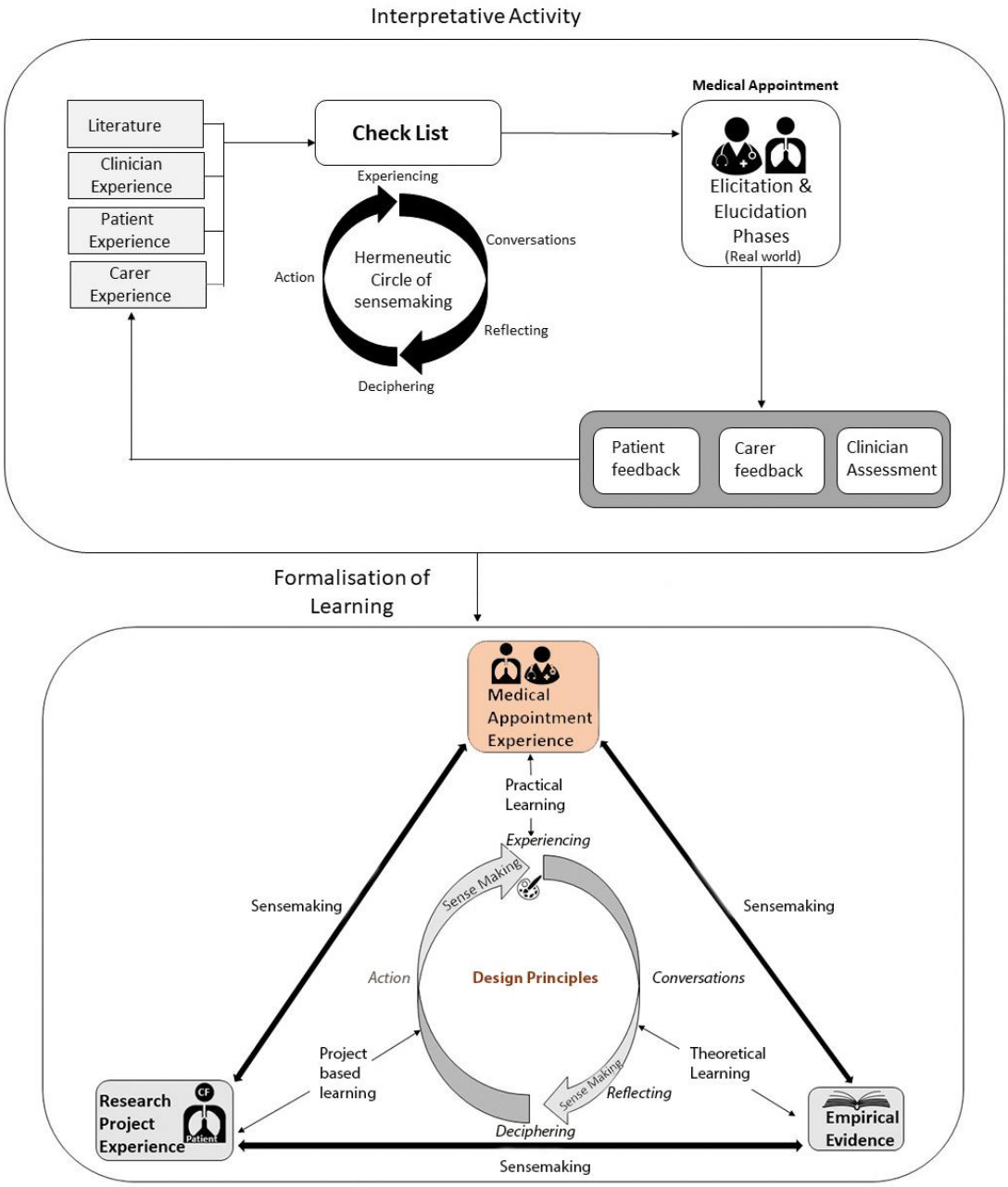


Figure 1-8 The iterative practice of 'build, intervention and evaluate' as an interpretative activity and the Formalisation of Learning (inspired by Hustad & Olsen, 2014).

Knowledge generation by way of artefact creation is of course vital for design research (Niehaves, 2007). Next (and throughout the study), I will show how the

creation of a simple check list artefact has not only made major impacts in practice, but has also contributed to the generation of new design knowledge that elucidates both the *"how and why"* of the artefact design. To address the research aim, and to satisfy the research objectives presented in Table 1-9, I adhere to an Action Design Research approach. Figure 1-8 gives a picture of the interrelated tasks shaping the backbone of the design approach utilised in this study. My design approach is of course guided by its purpose, which is to tackle a research aim. This entailed the iterative building, intervention and evaluation of an artefact in a real-world setting. The approach I have taken is buttressed by a rigorous research methodology, safeguarding the methodical standing of the study.

1.6.5. Research Outline

An outline of the research from my ADR journey is depicted in Figure 1-9 and incorporates a series of five papers that I have composed over the last three years, following four iterations of the artefact conducted as outlined in Figure 1-8. I will briefly visit each paper in our next section, and again later within the thesis. While one may expect the study to begin with a literature review, mine is somewhat different as it began with the problem of poor memory recall outlined earlier, which was impacting me and my fellow CF patients/carers. This is not by any means to say that I did not engage literature during my search for a solution, and in the design of the subsequent check list. The opposite is true, I was determined to find a solution, and so I became an avid reader from day one, continuously searching for answers, answers to what often seemed like a tsunami of questions entering my unwavering consciousness.

Paper 1 (Appendix A) focuses on the development of the artefact and was written after iteration 3 of the check list, with a submission to ECIS 2018 in November 2017 and, following acceptance, was presented in Portsmouth in 2018. My literature review resulted in two outputs (owing to number of research questions and its eventual size), Paper 2 (Appendix B – currently under review with the Journal of Decision Systems) and Paper 3 (Appendix C - accepted into the Journal of Decision Systems in July 2020). The rationale behind these two papers was deductive in nature as I wanted to understand '*how and why*' the check list had functioned so well for CF patients/carers within their medical appointments. The literature review was conducted over 9 months, and was, I believe, fundamental to the uncovering of '*how and why'* the check list was/is so successful. At this point in my research, I unearthed the different components of declarative long-term memory and their different roles within the medical appointment. This became a key motivator for iteration 4 of the artefact, where a check list booklet was created. Moreover, my discovery of the different components of declarative long-term memory also played a major part in Paper 4, where I show a representative set of design principles for the design of a check list for use by patients/carers to aid memory recall within the medical appointment.

Finally, Paper 5 (published in the Journal of Medical Internet Research in July 2020) constitutes a reflection of my ADR journey. Here I sought to capture the actual realities or '*ups and downs'* of the '*problem formulation'* stage of my ADR journey, which as I endeavour to expound, was often a source of intense frustration for me. Moreover, I wanted to convey the raw human side of my ADR research passage as honestly as possible, so that others may see research as a truly human

endeavour, with many '*twists and turns'*, but from which we may gain what is often lost, the rich tacit knowledge of human experience. Next, I outline the study's contributions to knowledge.

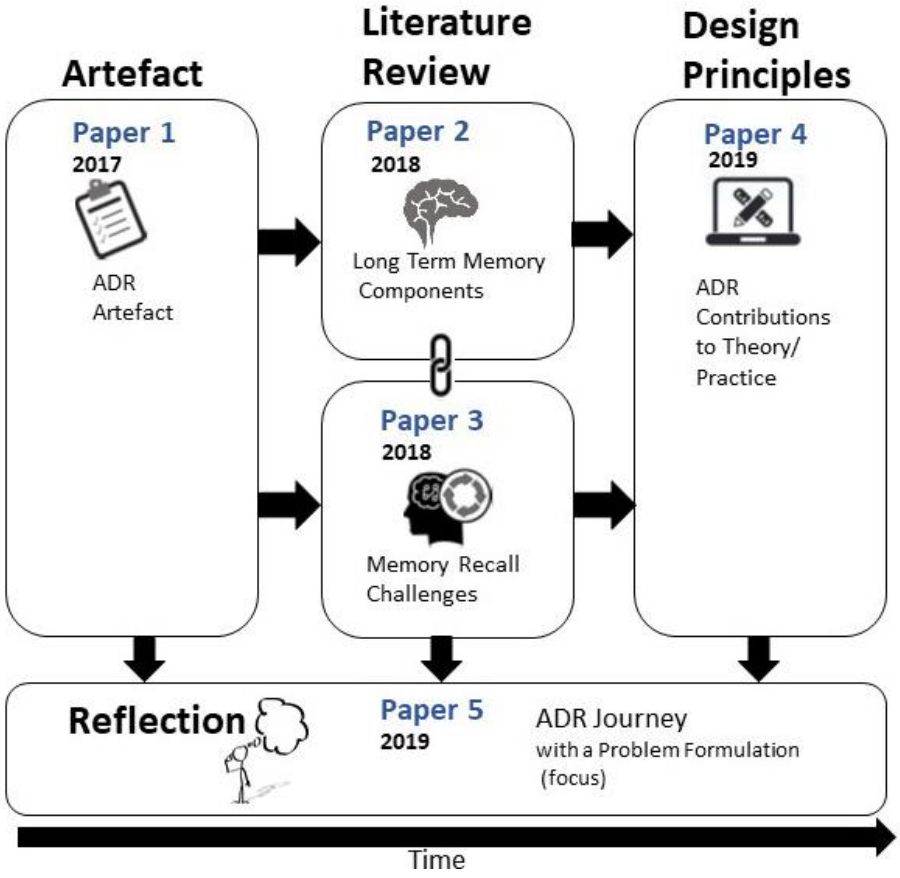


Figure 1-9 Papers in the study

1.6.6. Main Contributions to Knowledge in Brief

As one would expect my research contributions are dualistic in nature, having already visited the practical impacts (Section 1.3), I now outline the contributions to knowledge from each paper in Table 1-12. The main contribution to knowledge being the set of emergent design principles in Paper 4 (Chapter 3), the most novel of which is the unpacking of declarative memory into its components, where the

check list design actually maps to *"aid"* the memory type drawn upon by the patient/carer within the medical appointment. During the process of conducting this research study, two additional models emerged: a conceptual model of information retrieval/memory recall within the *elicitation* phase of the medical appointment (Appendix B & Appendix C), together with a visualisation of my reflection of '*problem formulation'* within the context of my ADR project (Paper 5 - Chapter 2).

Table 1-12 Study contributions to Knowledge

Paper	Contributions to Knowledge
1	Insights gained are an essential precursor to the creation of any effective digital solution.
2 & 3	Reveals the prevalence of long-term information retrieval/memory recall concepts, patient/carer memory recall challenges, including the disease states in which patient information retrieval/memory recall research has been conducted over the past 43 years.
	Conceptual model of information retrieval/memory recall within the *elicitation* phase of the medical appointment.
4	Presents a representative set of design principles for the design of a check list for use by patients/carers to aid memory recall. The most novel is the unpacking of declarative memory into its components, where the check list design actually maps to *"aid"* the memory type drawn upon by the patient/carer within the medical appointment.
5	Visualisation/model of reflection within the context of the ADR project, in tandem with the tacit knowledge of "*problem formulation*" within an ADR journey.

1.7. Structure of the Dissertation

This research study is structured using a series of papers and is depicted in Figure 1-10 below. It includes four main chapters: a chapter that introduces the overall thesis (Chapter 1); followed by Chapter 2, which contains Paper 5, a reflection of my ADR journey; subsequently Chapter 3 presents my 4th paper on the emergent design principles of the check list artefact. The thesis concludes with Chapter 4, a discussion and conclusion of study, in which I discuss my findings, contributions, the limitations of the study and future research. Of note is that we have inserted Paper 1 into Appendix A, Paper 2 into Appendix B, and Paper 3 into Appendix C. This was done as I felt that, while of course significant, these papers were more foundational in nature, with much of their essential richness captured in Chapter 1 to Chapter 4. However, a summary of each chapter/paper is now presented.

This research study starts with the current chapter, which starts with the research impacts to practice. Next, I present a brief context, background, research approach, the aims, research question and objectives. This is followed by a brief section on the research methodology, after which the outputs and knowledge contributions of the study are staged. After that, a short description of Chapter 2 (Paper 5) and Chapter 3 (Paper 4) are exhibited, followed by Chapter 4 in which I give an outline of the discussion and conclusion. Finally, a brief description of Papers 1 to 3 is considered.

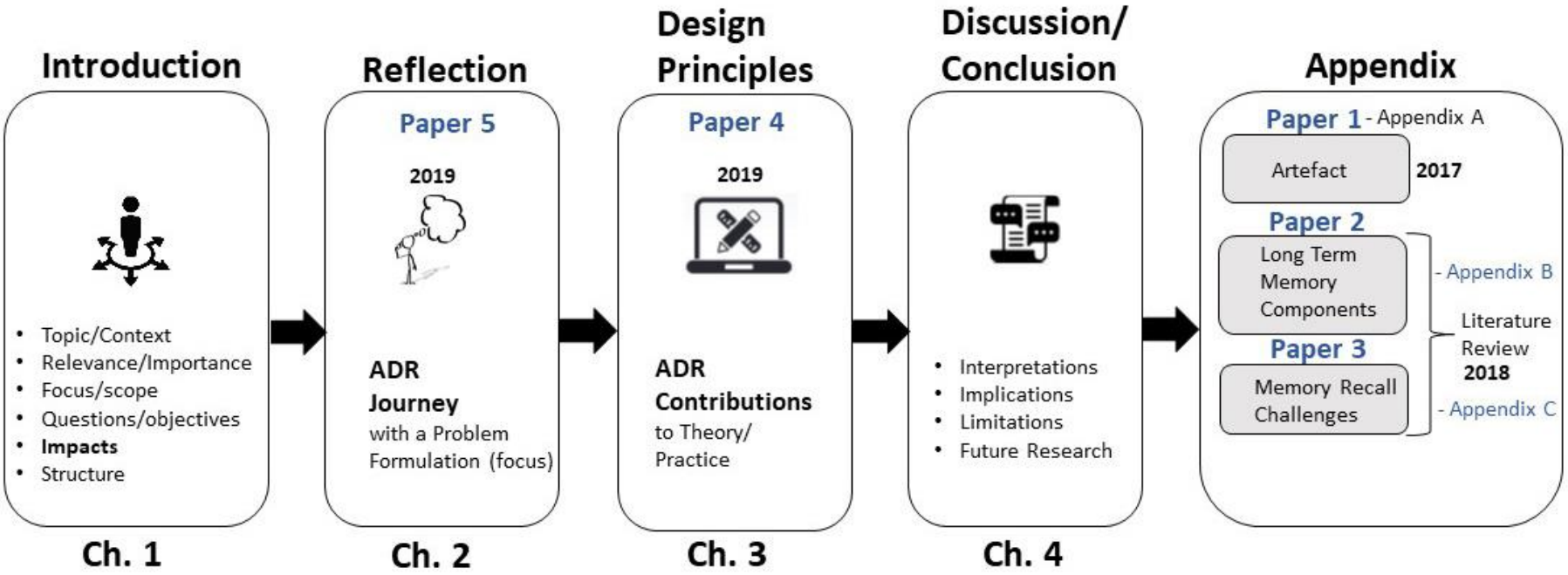


Figure 1-10 Structure of the Thesis

1.7.1. Chapter 2 - Paper 5 - The Research Method

Title: The "Tango" of Problem Formulation: A patient/researcher reflection on an Action Design Research journey. (Accepted (with minor revisions) and published in the *Journal of Medical Internet Research* (July 2020), DOI: 10.2196/16916).

This paper presents a reflection of my ADR journey, focusing on the *"problem formulation*" stage of the research. Playing a dual role, as both a patient and researcher, I reflect on my ADR experience of creating a simple yet impactful check list to aid memory recall of CF patients/carers within the medical appointment.

Using Driscoll's (2001) Model of Reflection to aid my musings, I portray my real-life un-sanitised ADR experience through a series of four vignettes. Through these extracts, I endeavour to include and portray the "*ups and downs*" of my ADR study, capturing the often-lost tacit knowledge of human experience, and begetting a sense of realism and humanity to my research, serving as knowledge contributions in their own right.

By imparting my story of *"problem formulation"* and its impact on successful outcomes within ADR, I hope that I may facilitate researchers to avoid making some of the mistakes that I have made, that they may come to appreciate the richness of viewing a problem through several alterative perspectives, and finally, that they may come to value and capture the real human stories/experiences within their own research.

1.7.2. Chapter 3 - Paper 4 - Check List Design Principles

Title: Turning challenges into design principles: A Check List for the chronic patient or carer. (Under review by the *Journal of Medical Internet Research).*

I begin the paper by taking a *People, Process, Technology, Data* view of two critical information phases within a medical appointment, in order that the reader may appreciate the complexities that exist therein, and why there exists such a vital need for information retrieval/memory recall by Cystic Fibrosis (CF) patients/carers.

My practice-inspired investigation presented in this paper is driven by the following motivation: how might I enhance CF patient/carer information retrieval/memory recall *within* these two information phases, critical to the success of the medical appointment? Building on extant literature, the paper presents a representative set of 10 key design principles (DPs) that emerged from my Action Design Research (ADR) study, where the check list artefact went through an iterative, build, intervention and rigorous evaluate process. The most thought-provoking DPs are as follows:

DP7. The correct use of colour is vital within a well-designed check list to facilitate information retrieval/memory recall and to draw the patients'/carers' attention.

DP8. To address an information retrieval/memory recall issue, one must understand and unpack declarative memory into its components and ensure that a design maps to *"aid"* the memory type drawn upon by the patient/carer *within* the medical appointment.

DP9. A booklet of check lists should be created after the final design iteration, in order to efficiently facilitate patient/carer episodic and autobiographical information retrieval/memory recall of medical appointments.

DP10. It is important to encompass a mental health assessment into a medical appointment check list, in order for the patient to self-reflect and report on their emotional state *within* the medical appointment.

The artefact has a number of design elements of value to practice and IS research, of which the most novel is DP 8; the unpacking of declarative memory into its components, where the check list design actually maps (Figure 1-11 -depicts this mapping) to *"aid"* the memory type drawn upon by the patient/carer *within* the medical appointment (Table 1-13). You will note that each line in Table 1-13 is given a number (*Comments No.*), and this number (for example C7) is then inserted in the correct plotted area in Figure 1-11. It is worth noting that both Table 1-13 and Figure 1-11 do not appear in Paper 4, as I believe there is a further paper to be considered and fashioned in connection with this discovery.

I believe the findings from this paper are both transportable and adaptable to the medical appointments of the 39 other chronic respiratory disease states, consisting of approximately 1 billion patients worldwide.

Table 1-13. Part of doctor - patient narrative, depicting the memory type drawn upon by the patient/carer within the medical appointment

Actor	Comment No.	Comment	Memory Type Used	Explanation
Doctor	C1	"Hi Michael, how are you? How have you been getting on since I last saw you?"	N/A	N/A
Patient	C2	"Not too bad, I had an infection, which has more or less cleared up with the antibiotic I took, but I still have a little bit of postnasal discharge which doesn't seem to be clearing up, which is quite annoying, normally it would be gone by now".	Autobiographical	Patient required to remember all episodes/events since last appointment.
Doctor	C3	"Ok, anything else to report? Any other changes, bouts or symptoms?"	N/A	N/A
Patient	C4	"No…...not really, nothing really comes to mind".	Autobiographical	Patient again uses Autobiographical memory for any relevant episodes/events since last appointment.
Patient	C5	"Oh, there was one thing I meant to say to you, since I went on Orkambi, I still get acid reflux every now and then".	Prospective	Following this cue from the doctor the patient's prospective memory kicks in resulting in a search for any information that was to be reported at this event.
Doctor	C6	"How often would you say you have had it? When did you last have it? What happened?"	N/A	N/A

Table 1-13 continued …

Patient	C7	"I would say I get it on and off."	Autobiographical	Patient tries to report on the temporal nature of acid reflux to the best of his abilities since last appointment.
Patient	C8	"For example, last Saturday night we had a pizza for dinner, it started about half an hour or so after, it was quite uncomfortable, especially in bed, it actually kept it awake for a while."	Episodic	Patient reports on the most recent occurrence of acid reflux which is very recent as a particular episode with greater detail for illustration purposes.
Doctor	C9	"To be honest that's not uncommon, you take one Omeprazole in the morning, don't you?"	N/A	N/A
Patient	C10	"Yes, at breakfast."	Autobiographical	Patient verifies that he takes this medication each morning.
Doctor	C11	"Ok, I would like you take one at night as well, is that ok?"	N/A	N/A
Patient	C12	"That's fine, I can enjoy my pizza so from now on. I must just remember now to take it at night."	Prospective	Patient acknowledges that he must add this to his treatment schedule and that this is something he must remember to take at night
Doctor	C13	"Yes, that should sort that out for you, just go easy on the pizzas…. Ok, anything else to report?"	N/A	N/A

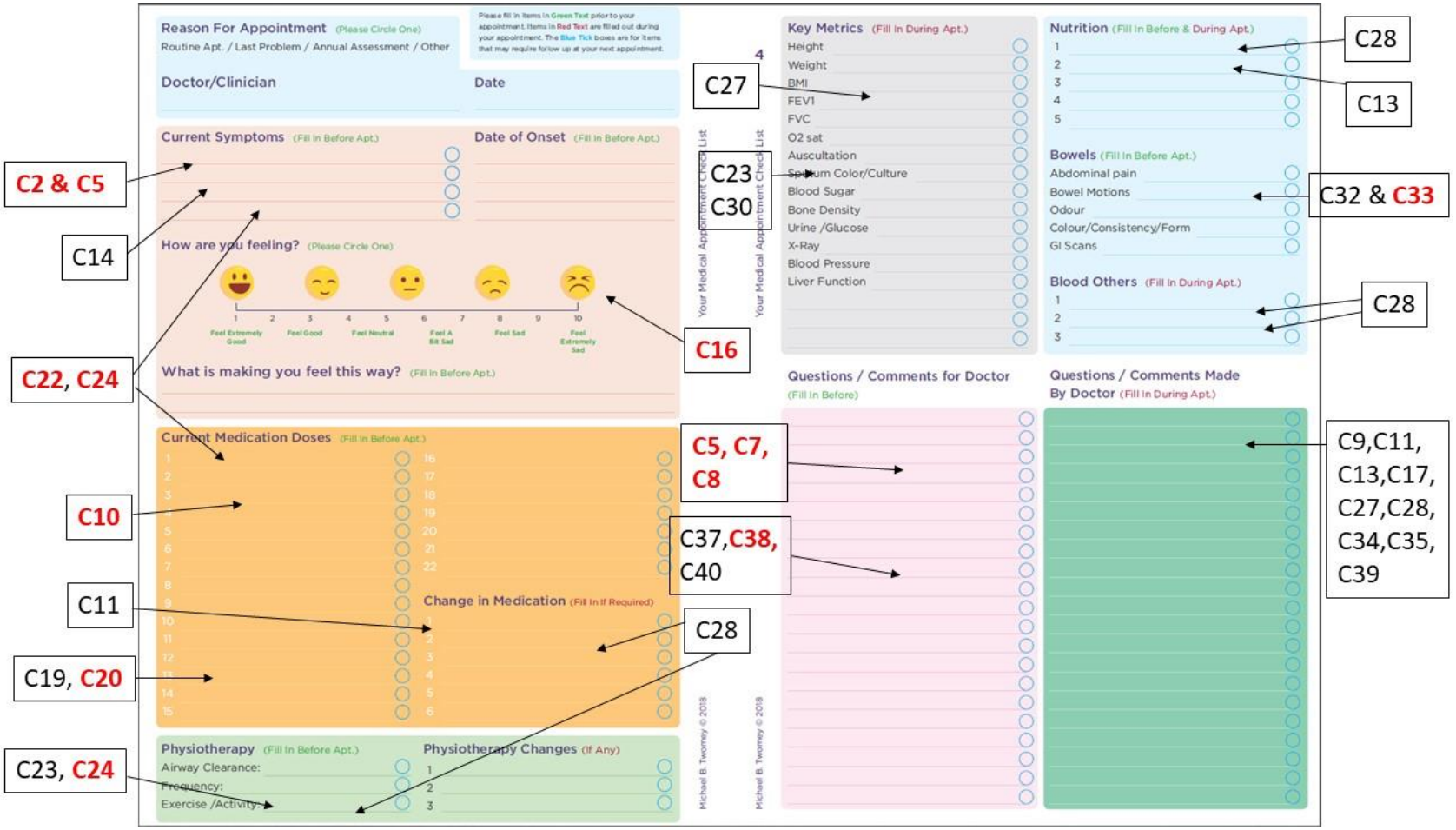


Figure 1-11 Check list mapping to memory type drawn upon by the patient/carer in Table 1-12

1.7.3. Chapter 4 - Discussion & Conclusion

The discussion and conclusion chapter stages a cross-paper analysis and a final consideration of my ADR study. Here I discuss the answers to my research objectives (a series of research questions), validate how I have addressed the overall aim of the study, and answered the following key question; *How might we augment Cystic Fibrosis (CF) patient/carer memory recall/information retrieval within the elicitation phase and elucidation phase of the medical appointment?* I also take into consideration the significance and implications of my findings, including the contributions to both knowledge and practice. Finally, I outline the limitations of my study and present the opportunities for future research, a vision of where I hope I (and others) may venture to next.

1.7.4. Appendix A – Paper 1 - The Artefact

Title: A check list designed to improve memory recall amongst CF patients/ carers. (Accepted (with minor revision) by the *European Conference on Information Systems* (2018)).

This paper explores; *"The memory recall/information retrieval of Cystic Fibrosis (CF) patients/carers within the medical appointment and the impacts a simple artefact can have on memory recall, stress and empowerment"*. Using Action Design Research, the artefact designed, built and evaluated to address the problem is a pretotype (a paper-based prototype) in the form of a Check List. Rigorous real-world evaluation by CF patients, carers and respiratory clinicians' points to the artefact's validity and shows its contribution to memory recall, a reduction in stress, and an increase in empowerment for both CF patients and carers.

1.7.5. Appendix B - Paper 2 - The Literature Review (part 1)

Title: Information Retrieval/Memory Recall *within* the Medical Appointment: A Review of the Literature. (Under review (third round) with the *Journal of Decision Systems).*

The basis of this paper is to probe the current literature to determine the frequency of long-term information retrieval/memory recall concepts *within* the medical appointment, including the disease states that have conducted research in the area, affording an analysis of research activities in order to identify the gaps in knowledge that currently exist.

Rigorous examination was conducted using Watson and Websters Concept Centric Matrix (2002) and Finney and Corbett (2007) open coding techniques, resulting in the identification of 227 concepts. The review draws attention to a variety of gaps in research that function as possible IS research prospects including areas of long-term memory i.e., Prospective memory and Autobiographical memory, disease states such as respiratory, renal and integumentary (all of which have many chronic patients attending appointments on a daily basis worldwide). The paper closes with a conceptual model of information retrieval/memory recall *within* the *elicitation* phase of the medical appointment that aids our comprehension of the information retrieval/memory recall process *within* this phase of the medical appointment (Figure 1-12).

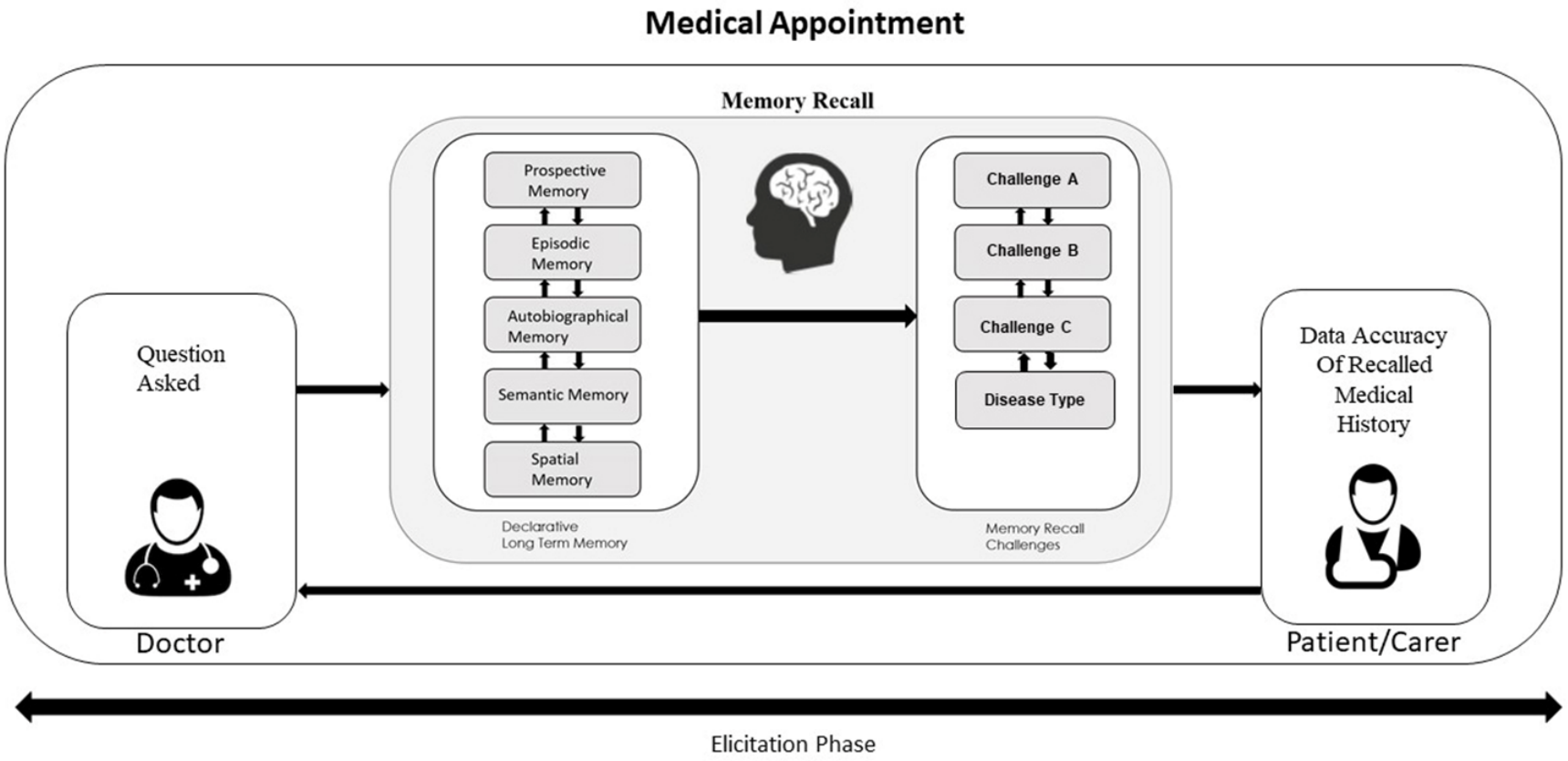


Figure 1-12 Initial conceptual model of Elicitation Phase of the medical appointment (advanced)

1.7.6. Appendix C - Paper 3 - The Literature Review (part 2)

Title: The Challenges of Information Retrieval/Memory Recall within the Medical Appointment: A Review of the Literature. (Accepted (with minor revision) by the *Journal of Decision Systems in July 2020*). DOI:10.1080/12460125.2020.1809781

This paper follows on from part 1 of our literature review (Paper 2), focusing on the memory recall challenges reported *within* the context of the medical appointment. Again, by means of rigorous examination through Watson and Websters Concept Centric Matrix (2002) and Finney and Corbett (2007) open coding techniques, our analysis points to the prevalence of four leading patient/carer memory recall challenges reported in the literature over the past 43 years; emotional state, health literacy, forgetting and disease type. The exploration also highlights the gaps in the area, serving as future research opportunities within the context of memory recall *within* this unique medical setting. Our analysis concludes by building on our conceptual model of memory recall in the *elicitation* phase of the medical appointment from part 1 (Paper 2) of our literature review in Figure 1-13, that serves to further augment our comprehension of the memory recall/information retrieval *within* this byzantine environment, also evoking future areas of enquiry.

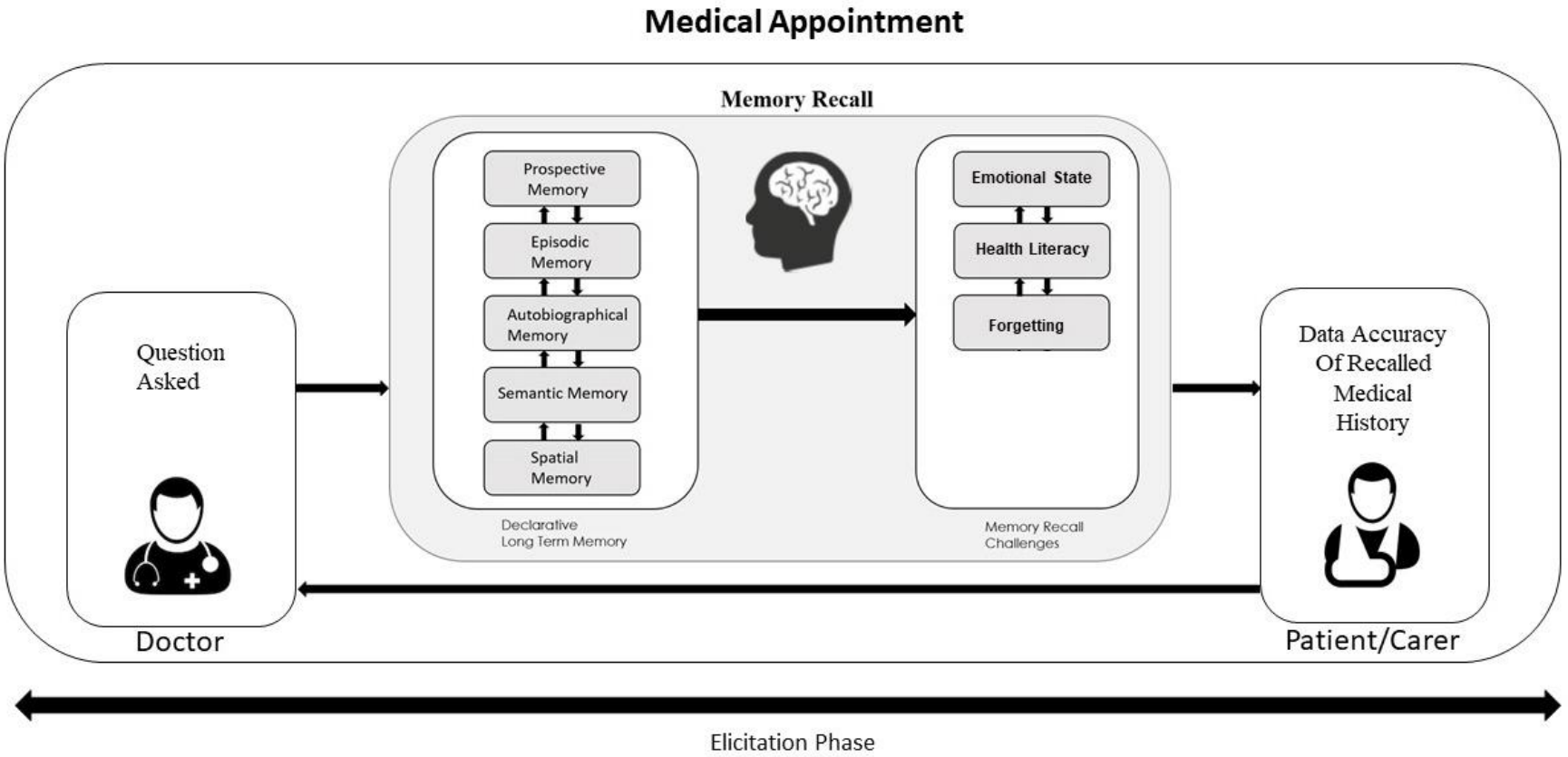


Figure 1-13 Conceptual model of Elicitation Phase of the medical appointment (advanced)

1.8. Conclusion

My first objective in this chapter was to provide an outline of the impacts of my research to practice (Section 1.3); followed by providing some contextual information on me (the researcher) and the motivation behind my study (Section 1.4). Next, I visited the research background, where I introduced the concept of memory recall/information retrieval and check lists (Section 1.5). Additionally, I established the scope of my memory recall analysis (that of the medical appointment setting), highlighting its relevance and importance.

The second objective of this chapter was to: (1) outline my philosophy of science, ethical considerations, stating the research aim and objectives that guide the research, as well as to outline the contributions to knowledge (Section 1.6); and (2) to describe the research method required to achieve the objectives (Section 1.6.4). In Section 1.7, the penultimate section of this chapter, I defined the composition of the research, incorporating the makeup of the thesis, a digest of each chapter, and the rationale behind the inclusion of each paper. Finally, this closing section, brings this chapter to a conclusion.

Next, in Chapter 2, I present Paper 5, a reflection of the "*problem formulation*" stage of my ADR journey.

Chapter Two

2. Paper 5: The "Tango" of Problem Formulation: A patient/researcher reflection on an Action Design Research journey.

2.1. Abstract

This paper reports on the reflections of the lead researcher, a 48-year-old with Cystic Fibrosis (CF), and aims to portray his real-life experience of a 10-month Action Design Research (ADR) project. Playing a dual role, as both a patient and researcher, the lead researcher reflects deeply on his ADR experience with particular emphasis on the "*problem formulation*" stage of creating a simple yet impactful check list to aid memory recall of CF patients/carers *within* the medical appointment.

Using Driscoll's (2001) Model of Reflection, a real-life un-sanitised ADR experience is carefully imparted via a series of four vignettes, including four key learnings, which highlight the connection between a meticulous considered approach to "*problem formulation"* and truly effective outcomes. By providing this rich account of *"problem formulation"* within ADR, it is hoped that this reflection will help researchers to better understand the complexity of "*problem formulation*" in design orientated research, to avoid making assumptions and becoming *"fixated on solutions",* and move instead to an endpoint where several possible ways of

examining a problem have been considered, explored, and understood. An endpoint, where through grit and determination successful end results are reached.

This paper advocates for the inclusion and portrayal of the actual realities or "*ups and downs"* of this dynamic and evolving stage of ADR, capturing the often-tacit knowledge of *"problem formulation"*. Begetting a sense of realism and humanity to ADR, serving as knowledge contributions in their own right. The lead researcher is the patient/researcher in this Action Design Research project. This is my story!

Keywords:

Action Design Research, Patient, Reflection, Problem Formulation, Check list, Cystic Fibrosis.

2.2. Introduction

It's a windy Saturday afternoon in February 2020, and I am busy packing up a box of check list booklets that I designed to aid Cystic Fibrosis (CF) patients/carers memory recall/information retrieval *within* their medical appointments. The box is on its way to the Royal London Children's Hospital, Whitechapel, London, for distribution to CF carers. Carers who know the reality of having a sick child in a medical appointment, and the stress of trying to remember a medical history, and the difficulty of trying to recall afterwards what took place *within* a medical appointment. I tape up the box carefully, making sure it is secure for its journey ahead.

A journey that would not have come to pass had I not been invited to present my ADR research at the International CF Clinical Conference held in Killarney, Ireland on the 30th January 2020. Out of that too, came the dispatching of the check list booklet to Spain, Sweden, Israel and Australia. There is no doubt the check list booklet is beginning to travel far and wide. Earlier, in January 2019, the booklet was distributed by Cystic Fibrosis Ireland to every patient/carer within the Republic of Ireland (1,300 CF patients). Afterwards, in April 2019, it was also shipped to the Czech Cystic Fibrosis Association and Austria for review.

Moreover, in October 2019, I was invited to present my research on the booklet to over 100 clinicians at a *"Hot Topics in CF"* conference held in Birmingham, England. Nevertheless, the real impact of the check list booklet is best depicted by the mother of a 7-year-old CF child:

> *"We just wanted to say we received our medical appointment check list today, and we just wanted to say THANK YOU so much, we love it and it's going to be incredibly handy for us, although it's just a book to our little boy now, in a few years he'll know how great and simple it is as well".*

As I contemplate same, a warm feeling envelops me. I feel I'm beginning to make a difference, a difference to people like me. The box is ready to go, and a thought enters my mind, "*So was my ADR journey easy?"* The answer is definitely no. *"Did it take determination and patience?"* Yes, for sure! *"And did I sometimes think of giving up? Did it test me to my limits?"* I would have to say yes on both accounts. So how do I account for the success of the check list booklet? Earlier I mentioned determination; I was unyielding in my quest to understand the problem, the problem that I and others like me experience every time we are in a medical appointment. To help you understand however, I need to take you on a voyage, a voyage of reflection. It is only by coming on this journey that you will come to comprehend the endpoint, where through grit and determination success was achieved.

Humans have always reflected on experiences and feelings." (Davidson & Sternberg, 2003 p.44). According to Boud, Keogh and Walker (1985, p.43) reflection is: *"an important human activity in which people recapture their experience, think about it, mull it over and evaluate it".* As a researcher I felt an obligation to share my un-sanitised lived experience of *"problem formulation"* in Action Design Research (ADR), not only as a practitioner but also through the eyes of a patient researcher living with a chronic illness.

To this end, I found that a reflection would be the most appropriate instrument to aid me with the *"mental process of trying to structure or restructure"* (Korthagen, 2001, p.58) my real-life experience of *"problem formulation"*, to put together or capture the *"existing knowledge or insights"* (ibid) from the project that I lived through over a 10-month period. I hope that the insights imparted herein may serve, not only as insightful to ADR practitioners in their *"problem formulation"* endeavours, but also to highlight the importance of this stage of ADR to achieving successful outcomes. Moreover, I hope that any patients reading my reflection may be inspired to enter the stimulating world of research, making real world impacts within their own patient communities, as I have strived to do in mine.

I have structured the paper as follows. Firstly, I present a very brief background on Action Design Research (ADR), the methodology that I utilised in my research exploration, going somewhat deeper on the *"problem formulation"* stage of the methodology (the focus of my reflection). Next, I endeavour to set the scene, giving the reader a deep candid sense of the patient researcher behind the reflection, followed by a very brief section on why a reflection was the correct tool for my deliberations, and the rationale behind the model of reflection I selected. I subsequently organised my reflection through a series of four vignettes, which are used to explain the lessons that I learned from my experience of *"problem formulation"* within ADR and how crucial this was to the effects my research is now having. Finally, I bring my musings to a close in the concluding remarks section of the paper.

2.3. Background

2.3.1. Action Design Research

Design science research (DSR) accentuates a "*construction-oriented*" interpretation of information systems (IS) research in which, at its core, lies the design and build of innovative IT artefacts, and which is deemed appropriate when research aims to produce artefacts that address so-called "*wicked problems*" or ill-structured problems (Hevner et al., 2004). This approach, whilst providing IS researchers with the ability to go beyond mere elucidation towards research that spawns design knowledge relevant to practitioners (ibid), still fails to "*fully recognize the role of organizational context in shaping the design as well as shaping the deployed artefact*" (Sein et al., 2011, p.38).

And so, in their 2011 seminal paper, Sein et al. proposed a variant of DSR (Figure 2-1) they called action design research (ADR), that clearly acknowledges IT artefacts as "*shaped by the interests, values, and assumptions of a wide variety"* (Orlikowski & Iacono, 2001, p.131) of stakeholders whilst also retaining the essence of design research (DR). ADR targets the creation of innovative artefacts in an "*organizational context*" but at the same time produces knowledge contributions from the intervention while tackling a problematic situation (Baskerville & Wood-Harper, 1998; Hevner et al., 2004). Sein and Rossi argue that the "*embedding of the context in the design through intervention in an organisation, a single-entry point (problem-centered), and inductive epistemology, is the characteristics of ADR that validate knowledge claims of emergent knowledge co-produced with practice"* (Sein & Rossi, 2018, p.2).

ADR differs from other design approaches insofar as it draws on design science research (DSR), which centres on the utility of an artefact, and action research (AR) which primarily focuses on learning from an environment, believing that "[t]*he only way to produce conditions of practice is to move to practice*" (Wieringa, 2010, p.72). Moreover, at the core of ADR is inquiry with rigorous evaluation, which is highly iterative in nature, consisting of nested loops (Sein & Rossi, 2018), where each iteration concludes with a consideration of the artefact. This evaluation acts as the impetus for thorough *reflection and learning*, which then feeds back into "*problem formulation"*, thereby challenging *"organizational participants' existing ideas and assumptions about the artefact's specific use context in order to create and improve the design"* (Sein et al., 2011, p.42). It is these very characteristics that make ADR so successful as a methodology.

It comes as no surprise therefore, that ADR has been used very effectively in a wide array of research projects and, "*because of its ever-expanding applications, the ADR concepts and process model continue to grow and evolve to meet the demands of new and challenging environments*" (Mullarkey & Hevner, 2018, p.1), including those within the health domain. Take for example, Bretschneider et al. (2015) successful solution that helps to leverage patients' innovative ideas potential better than traditional communication forums.

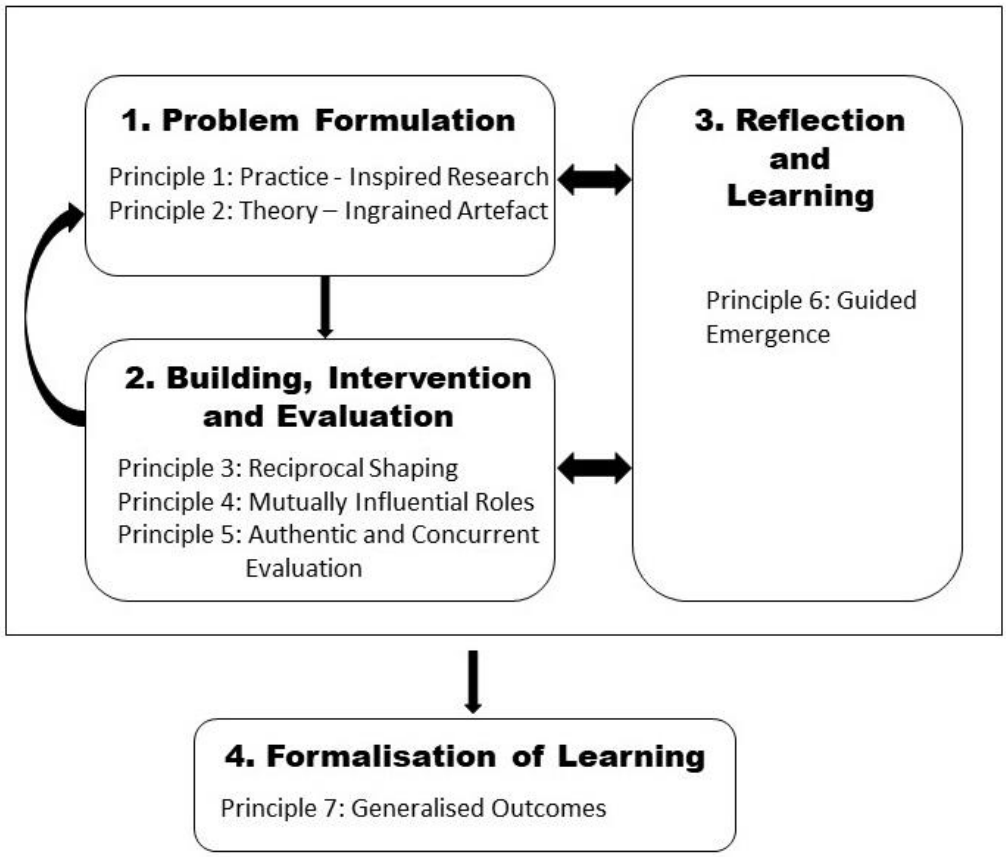


Figure 2-1 ADR Method: Stages and Principles (Sein et al., 2011)

As a pragmatist who is "*more interested in utility and usefulness than in an abstract notion of truth*" (Ågerfalk, 2010, p.251), I deemed ADR as a suitable methodology for my research endeavours as it is grounded in and grounds research from practice, academia and empirical data. Its primary focus is on learning from designing an artefact or intervention within an environment. This is important as it was imperative that the solution that I created worked *within* the complex environment of the medical appointment. My reflections later on in this paper reveal my experience of ADR as a patient/researcher, and serve to contribute to the recent open and engaging discussions regarding "problem *formulation*" in ADR, consistent with the original authors contention, who contend that ADR "*is still an*

open endeavor" (Purao et al., 2013, p.79). But first let us delve into the "*problem formulation*" stage of ADR in greater depth.

2.3.2. Problem Formulation

In 1998 Berthon et al. stated that "*problem formulation*" was the least researched of problem-solving activities. In 2018, Mullarkey & Hevner reported on the challenges they had regarding the "*problem formulation*" stage of ADR. More specifically, they discovered that they "*needed to better understand the problem space*" (Mullarkey & Hevner, 2018, p.7) and maintained that Sein et al. (2011) ADR model required an explicit "*diagnosis*" stage (with a clear separation from design) model, "*to analyse the importance of the problem domain and the relevance of the IT solution class to research and practice*" (Mullarkey & Hevner, 2018, p.9).

What is Problem Formulation?

Simply put, *problem formulation* = problem ID (perception) + problem definition (conceptualisation) + problem structuring (instrumental reasoning). "*The first requirement with any complex problem is to try and understand it as a totality. How has it arisen, and why? Where is it going and what route is it taking? Is it changing its nature or structure as it develops?*" (Mumford, 1998, p.265). The "*problem formulation*" stage in ADR (Table 2.1 presents the tasks in the stage) identifies and conceptualizes (using both divergent and convergent metacognitive processes) a research opportunity based on existing theories and technologies (Hevner et al., 2004), where the research activity is said to be problem inspired (Markus et al., 2002; Vaishnavi & Kuechler, 2007).

So how important is the "*problem formulation*" stage of ADR? The value of a suitable definition has been established empirically (Volkema, 1983). "*The more of the context of a problem that a scientist can comprehend, the greater are his chances of finding a truly adequate solution*" (Ackoff, 1956, p.265-266). Mintzberg et al. argue that "*problem formulation*" as "*probably the single most important routine, since it determines in large part, however implicitly, the subsequent course of action*" (Mintzberg et al., 1976, p.274). While Mitroff et al. (1979) maintain that problem forming and defining are as critical, if not more so, than problem solving, this is probably not surprising as our understanding of a problem greatly influences our selection of solutions (Kaufman & Sternberg, 2019) and helps avoid Type III errors, solving the wrong problem (Smith, 1989).

Table 2-1 Tasks in Problem Formulation of ADR -Sein et al. (2011)

Stage	Tasks
Problem Formulation	(1) Identify and conceptualize the research opportunity (2) Formulate initial research questions (3) Cast the problem as an instance of a class of problems (4) Identify contributing theoretical bases and prior technology advances (5) Secure long-term organizational commitment (6) Set up roles and responsibilities

Why is Problem Formulation so challenging?

According to Mitroff and Featheringham (1974), one of the most important challenges of the problem-solving activity is solving the 'wrong' problem by adopting a formulation that is either too narrow or inappropriate. So, one may well ask why "*problem formulation*" is so challenging? In Table 2-2, I have tried to encapsulate some of the key challenges to "*problem formulation*" that have been reported in literature.

Table 2-2 The Challenges of Problem Formulation

Challenge	Reference
Problems, by their very nature, are complex and ill-structured.	(Kilman & Mitroff, 1979; Lyles & Mitroff, 1980; Watson, 1976)
"In real life there is not a single, static, well-defined problem, but a constantly changing problem".	(Simon, 1977, p.239–240)
"The capacity of the human mind for formulating and solving complex problems is very small compared with the size of the problems whose solution is required".	(Simon, 1957, p.169)
Stakeholders may have conflicting interpretations of a problem resulting from different life experiences, competencies, goals, and values.	(Smith, 1989)
Human biases: "*fixated on these unwarranted assumptions, and this fixation interferes with the insight needed to solve the problem".*	(Weisberg & Alba, 1981, p.169)
People often are too quick to move on to evaluative stages of problem-solving rather than gaining a complete understanding of the problem.	(Basadur, 2004)
"We may be too ready to re-use features of known existing designs, rather than to explore the problem and generate new design features."	(Cross, 2007, p.104)
People often only identify the most obvious symptoms, or those to which they are most sensitive, resulting in the problem being described inappropriately.	(Mitroff & Featheringham, 1974; Watson, 1976)
Most companies aren't adequately thorough in actually defining the problems they are trying to solve.	(Spradlin, 2012)
"*Problem formulation*" has been shown to be highly dependent on the mode of problem presentation.	(Kuechler & Vaishnavi, 2006; Roy & Lerch, 1996; Dilla & Stone, 1997)
Changing problem presentation modes has considerable effects on mental model formation, where Simon and Hayes (1976) found that *"innocent changes in language had major effects on problem formulation".*	(Kuechler & Vaishnavi, 2006; Simon & Hayes, 1976, p.964)

How might problem formulation be done better?

In their ADR Process Model Mullarkey & Hevner argue that every iteration should go through "*problem formulation*" and that reflection and learning should also be executed in every cycle – mainly as it informs the "*problem formulation*" for the next ADR iteration (Mullarkey & Hevner, 2018). They also include a fourth ADR stage *Evolution* as a means to address the very temporal and evolving nature of both the artefact and the problem environment.

Sein & Rossi (2018, p.4) agreed that these modifications were a "*valuable*" addition to their initial model (which did not go into details) in terms of making it more "*transparent*" and "*accessible to researchers*", they do however point out that this was intentional "*because in launching a new method of doing DSR, we wanted to keep it at a broad enough level of abstraction to allow the actual application of the method to emerge in use*".

When several stakeholders are affected by a problem, all viewpoints must be taken into consideration for a solution to be deemed successful (Smith, 1989). After declaring the problematic gap, it is advised to specify evidence supporting the presence of that gap. Indeed, Brody (1982) raises the question should problem statements include an "*as evidenced by*" clause? Moreover, Mitroff et al. (1979) advocate the use of assumptional analysis to question any assumptions, projections and explanations lying beneath the problematic statement, while Lyles and Mitroff (1980) also propose that alternative views of the problem be sought to improve "*problem formulation*".

Utilising conceptual processing and mental models is also encouraged in DSR literature (Venable et al., 2012; Peffers et al., 2012) to assist the "*problem formulation*" stage. Interestingly, Lesgold (1988) discovered that experts expended additional time deciding an appropriate mental model of a problem than did novices. This may be explained because "*what we understand and how we understand a situation depends on the information we bring to a given situation, and the longer we think about the situation the more its cognitive representation changes. It may be assumed that cognitive elaboration activates more schemata*" (Aaltonen, 2016, p.29) and hence enriches "*problem formulation".*

Like any good story it is important to first set the scene, facilitating an appreciation for key contextual elements of the story that I feel are important to comprehend, and so we now move to the next section, the research setting.

2.4. Research Setting

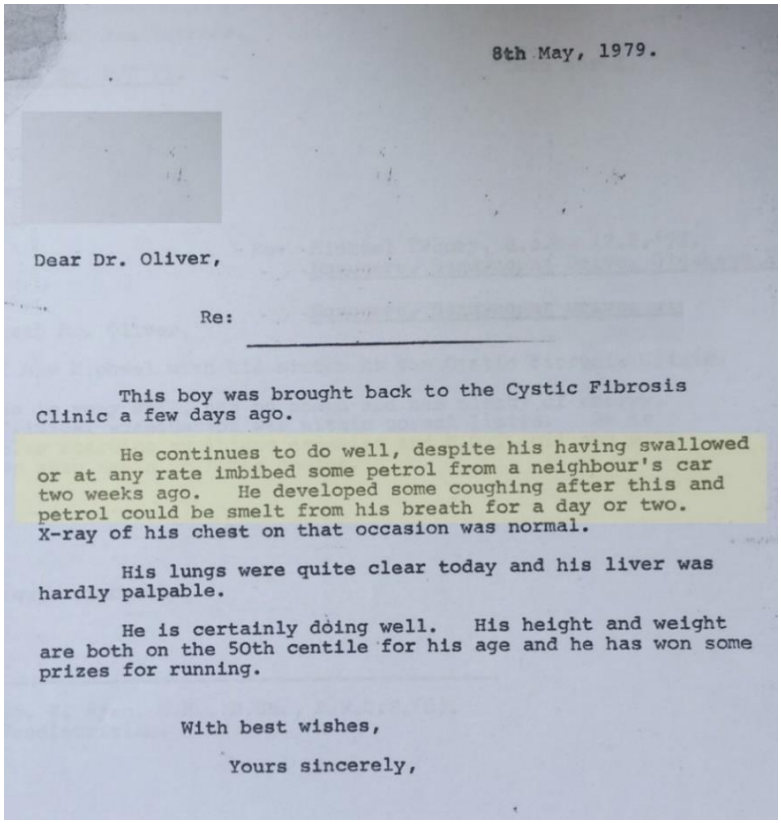
It's 11.27am, it's a pleasant day outside, the sun is shining, and summer shows visible signs of its arrival in the garden outside, with many perfumes and aromas creating an exciting olfactory feast. It seems appropriate that I start this paper on this date, 25th May 2019, as it is my sister Janes 50th birthday, and she was one of the key motivators and sources of inspiration for my research journey. Unfortunately, I cannot celebrate this special occasion with her as she passed away with Cystic Fibrosis (CF) on 29th July 1997. I feel an intense sense of sadness mixed with emotions of happiness as the memories of her sail across the horizon of my memory.

I have witnessed the effect that her passing has had on my family. I have seen the agony and the physical effects that the death of my sister has had on my dear parents. I will never forget that day. I will never forget the life-support machine flat-lining, the tears, the pain in that intensive care unit; it will live with me forever. The experience of her end has left an indelible mark on me, not only because of the pain of her passing but also as I have CF myself. I have also lived through the hardship that one endures with CF. I have faced the dark shadows that come into a room when gasping for breath, where one's mortality becomes all too real.

After my sister's death I had a choice; to let this disease define me and become a bitter, negative person who craved self-pity, or to embrace the positive aspects that the disease had carved out or sculpted into my heart and mind. You might ask what do I mean by positive? I mean the appreciation for life, for family, for fun, for being able to breathe. I mean the ability to empathise with others, to be compassionate to another people's suffering. I wanted to make a difference, to give something back, as others have given to me, which has resulted in my own good health. I wanted to help others with CF who are travelling on their own difficult journey, a passage that has many dark and difficult days.

While I admit that living with CF is not always easy, I have always been a fighter, I had to be! I would not give into myself or my condition. I love life too much. Life has so much to offer, that so many take for granted. Moreover, I think when you are faced with the very serious question of your mortality at a young age, you learn to be truly grateful for the gift of life. That is the real reward of a chronic condition, and it became the match that ignited the fight and passions within me.

My appetite for learning and wanting to help other CF patients/carers was really kindled in October 2014 when I returned to postgraduate executive education, and it continues to burn brightly. For those who know me best it probably comes as no surprise that I have become a researcher. Even at an early age I was quite inquisitive and sought to explore and understand the world around me. However, it may surprise you to know that my first attempt at research failed miserably. I was just seven years old and I was trying to make sense of how one could get a liquid (in this case petrol) to rise in a tube. I thought it fascinating until I imbibed/inhaled a gulp of it, and also flooded the neighbours' driveway. I was the talk of the neighbourhood for about a week. Thankfully, it did not end in complete disaster, nor did it quell my inquiring mind, but I am sure I scared my poor parents half to death. This event became known as the "*petrol episode*" (Figure 2.2 – in yellow).



8th May, 1979.

Dear Dr. Oliver,

Re: _____

This boy was brought back to the Cystic Fibrosis Clinic a few days ago.

He continues to do well, despite his having swallowed or at any rate imbibed some petrol from a neighbour's car two weeks ago. He developed some coughing after this and petrol could be smelt from his breath for a day or two. X-ray of his chest on that occasion was normal.

His lungs were quite clear today and his liver was hardly palpable.

He is certainly doing well. His height and weight are both on the 50th centile for his age and he has won some prizes for running.

With best wishes,

Yours sincerely,

Figure 2-2 The petrol episode

It is a day that we at home do not speak of too often, except to remind me that I am capable of some awful blunders and that research does not always go according to plan. However, I like to think that that day in May 1979 gives you the reader a little glimpse of the character that I am; spirited, curious and not afraid to explore!

Many would contend that as a CF patient with over 48 years' experience living with CF that I was the perfect candidate to research/explore and understand the associated problems of memory recall *within* the medical appointment. And yes, there is no doubt that I had the ability to impart rich CF related information to the project, however quite quickly I became very cognisant of the fact that my illness journey (while sharing similarities with others) was my own unique voyage, with all the biases of any individual. Recognising this and taking advantage once again of the robust ties that I had within CF community, I drafted two CF carers into a design team and a CF clinician to reduce the bias that I brought to the ADR project and to enrich the knowledge of the collective.

My patient inspired investigation was driven by what eventually became the following motivation: how might I augment Cystic Fibrosis (CF) patient/carer memory recall/ information retrieval *within* the *elicitation* and *elucidation* phases of the medical appointment? My primary focus eventually (discussed later) became the design of a check list artefact over a 10-month period (Sept. 2016 - April 2017). A check list that would not only ameliorate the challenges of memory recall *within* the CF medical appointment, but also augment our actual comprehension of same.

My research activity occurred in four iterative ADR cycles. Each iteration comprised of rigorous naturalistic evaluation, involving subjective ex-post

interviews between myself and the evaluation team (seven CF adult patients and eleven carers of CF children), regarding their use of the artefact *within* their real-life medical appointments. In these evaluation interviews I used qualitative metrics evaluating completeness, usability, robustness, and impact (Appendix D) that helped shape our sense-making process.

In tandem with this, I also sought expert opinion from clinicians on their appraisal of the check list design, and its subsequent use by CF patients/carers. These activities were followed up with learnings, reflections, and frequently additional consultation with literature, followed by conformity by the design team on the design enhancements to be executed in any subsequent iteration, incorporating the intervention strategy of same.

I now visit section 4 of the paper, starting with the model of reflection I opted for, and the reflection (through 4 vignettes) on "*problem formulation*" within my ADR journey and its significance to efficacious outcomes.

2.5. Reflection on my ADR journey

2.5.1. Model of Reflection

In 1988, Gibbs argued that it was "*not sufficient simply to have an experience in order to learn, without reflecting upon this experience it may quickly be forgotten, or its learning potential lost. It is from the feelings and thoughts emerging from this reflection that generalisations or concepts can be generated. And it is generalisations that allow new situations to be tackled effectively*" (Gibbs, 1988, p.9). After all, "*we learn from reflection on experience. Reliving of an experience*

leads to making connections between information and feelings produced by the experience" (Dewey, 1933, p.78).

Many of the seminal works on reflections/reflecting served as the initial stepping-stone of my reflection in this paper. Whilst many models exist as possible viewpoints from which one might reflect, I opted to use Driscoll's What? Model of reflection (Driscoll, 2001) (Figure 2-3), as I felt it resonated with me the most as an instrument to steer my reflection through the often-murky waters of my inner self.

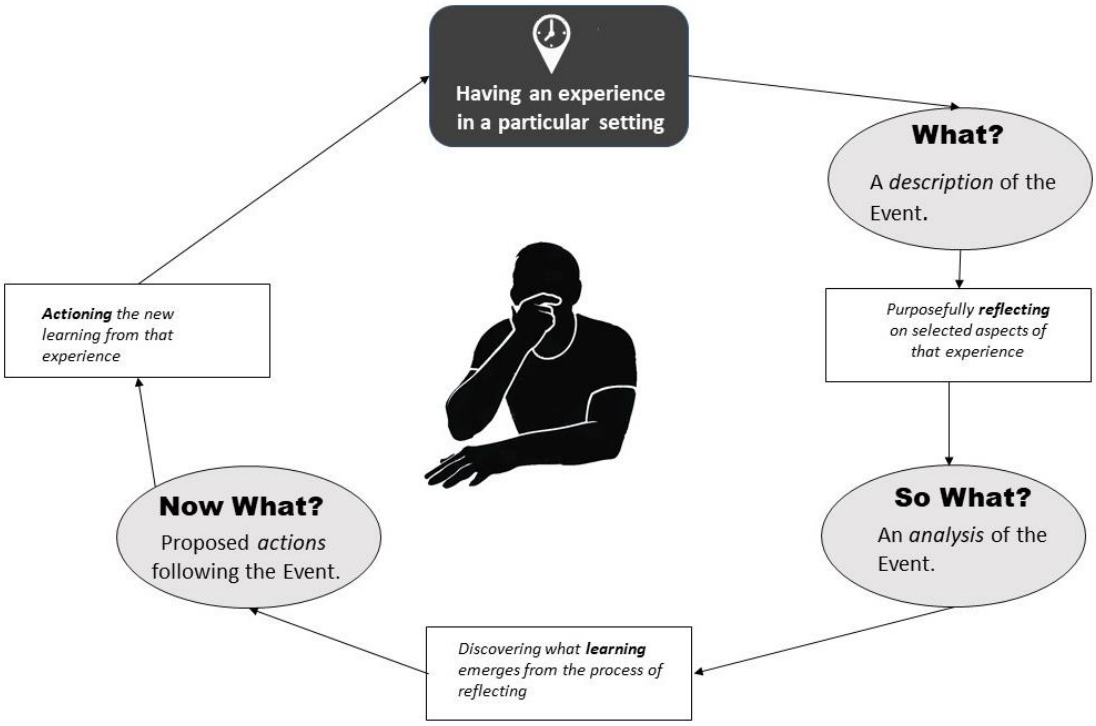


Figure 2-3 The What? Model of reflection (adapted from Driscoll, 2001)

Furthermore, as a reflection can be very personal and tacit in nature, it can be quite a challenging exercise or experience in and of itself. For example, it can take considerable time and may be painful, and may even create a crisis of confidence (Maclean, 2012). That being said, it "*offers distinctively grounded opportunities to*

pursue the connections between biography and social structure" (Anderson, 2006, p.389). Moreover, "*reflection allows us to draw conclusions about our past experiences and develop new insights that we can apply to our future activities*" (Wade & Yarbrough, 1996, p.361).

Therefore, I felt it important to select the correct lens for me, one that would facilitate the recapture of my real-world experience rather than curtail/hinder the narration of my ADR journey as a patient/researcher. I reflect (using a series of four vignettes and Driscoll's model) on an aspect of my ADR journey that I feel quite passionate about, that of the "*problem formulation*" stage of ADR, and of course its value to the fruitful outcomes of my study. I also have added a lesson learned in each vignette; this is merely to reinforce the key message I wish you, the reader, to take away from my meanderings.

Whilst my ADR journey is still ongoing, the paper-based check list aspect of the project, the majority of which took place over a 10-month period (from Sept. 2016 - April 2017), culminating in the creation of a check list booklet in January 2019, is for now complete. It is this period that I wish to reflect upon, a "*reflection on action*" or a reflection through review as described by Schon (1983), the process of review to inform learning (ibid).

However, it is also important at this juncture to accentuate how and where these vignettes and learnings arose in the context of the overall ADR project. To this end, I include a simple diagram (Figure 2-4) which depicts the vignettes and learning in the context of the emergent, cyclical nature of the ADR project and its eventual outcomes. While this reflection focuses on the "*problem formulation*" stage of

ADR, it is critical to never lose sight of the fact that this stage moved in tandem with the other key stages of ADR.

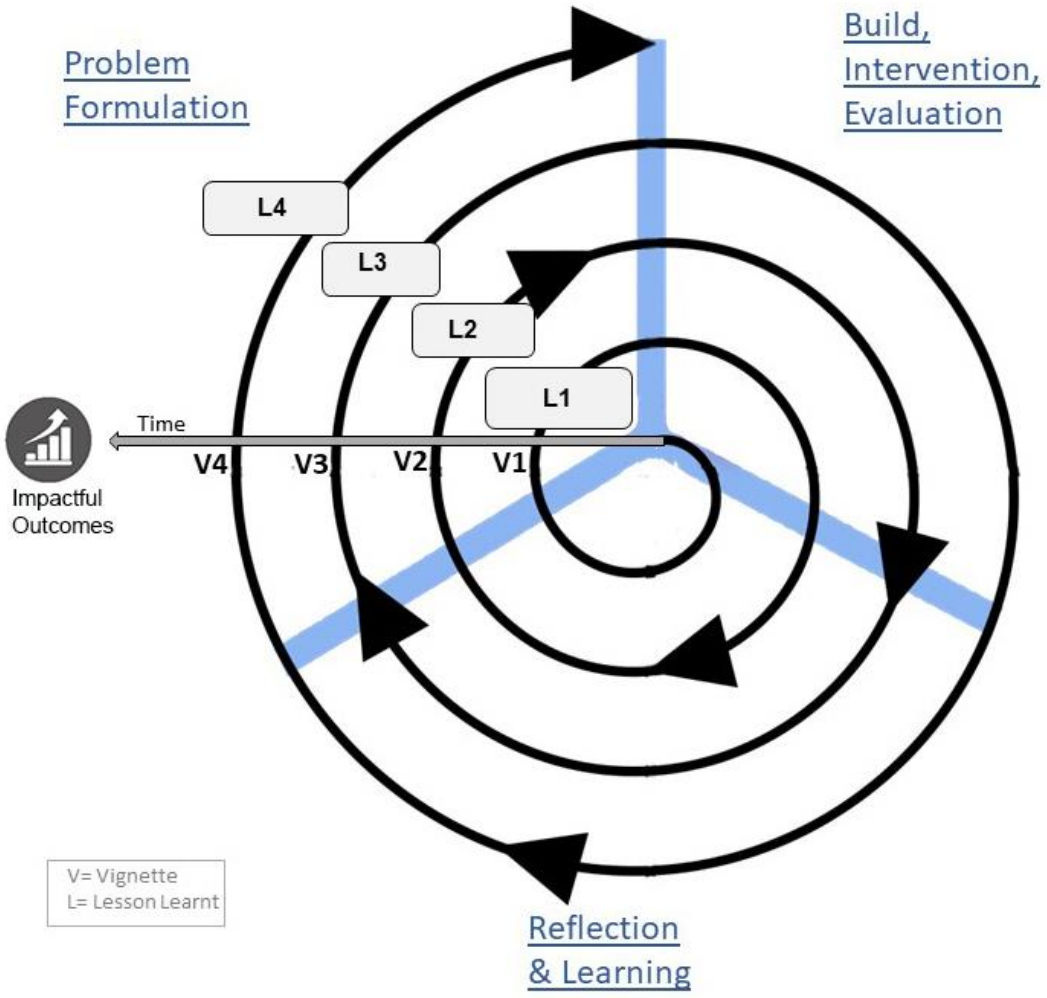


Figure 2-4 Visualisation of reflection within the context of the ADR project

These stages of ADR are akin to dancers performing the Tango, moving together in a closed embrace, individually and yet as one, influencing each other, each receptive to the others movements, shaping and being shaped by each other, all to a combination of an on-and-off-beat rhythm. It is in this spirit that I wish the reader to embark with me on my ADR journey. While I try to minimise the use of any

references, where I have used them, it is merely to enforce or enrich the musing of my ADR journey. And so, we move to my first vignette.

2.5.2. Vignette 1: Tragic Thursday - September 2016

What happened?

It was the 8th September 2016. I was giving a presentation to my class on my efforts to date. I stood there like a proud peacock, chest out, boldly claiming the problem statement to be as follows:

"There is currently no Patient Electronic Medical Records (PEMR) System that caters for the needs of CF patients/carers".

And so, CF patients/carers needed an app to manage their medical data. What is more, my design team and I were going to deliver it. We had created a number of wireframes for each screen of the app and here I was presenting them, "*at long last CF patients/carers would no longer struggle in their medical appointments when asked by doctors about their medical histories*" I said. Moreover, "*when they leave the medical appointment, they will not struggle to remember the information imparted to them by the doctor, it will sit on their phones/tablets and eventually in the cloud*".

And then it came, "*I'm not convinced, I don't think they will use it, I don't think you have a handle on this yet"* my innovation lecturer said. It was like he had pulled the rug from under me. I stood there shocked! The conversation that ensued between me and the lecturer (I'm embarrassed to say) got somewhat heated, and what made the whole situation worse was it all happened in front of the entire class!

I returned home; the day had not gone as planned; I was very frustrated and quite upset; I had been publicly challenged regarding my solution and indeed the problem I thought I was trying to solve. I was now sitting in the kitchen with my head in my hands, I was not in a good place. Why was I having such difficulties with the "*problem formulation*" stage of ADR? My wife and child came into the kitchen and knew by my demeanour that all was not well. "*What happened, did the presentation not go well?"* she asked. "*No, it was awful*" I replied. "*Let's talk later*" she said, with a quick glance at our little boy.

Later on, that evening, I proceeded to give her all the gory details of what had happened. However, I did not realise my little boy (who was seven and a half at the time) was listening, as he had left the kitchen and had gone upstairs to his bedroom prior to my regurgitation of my day. But as you know, children occasionally have the happy knack of overhearing or eavesdropping on discussions that they should not be privy to. This, despite our best efforts to protect them from the trivialities of adult conversations. And so, after ascertaining the gist of what had happened to me, he enters the kitchen with the swagger of a man who was going to expound some wonderful insight, and says, "*Daddy wouldn't you think that after all the trips to the doctor that you have had, that you would understand what happens at a medical appointment?*". I was left dumbstruck. I now refer back to that particular day as "*Tragic Thursday*", and yet on reflection there was nothing tragic about it, in fact the complete opposite is true; from that day onwards, my eyes were going to be opened! I was going to realise the importance of this day as a turning point in my research.

So What?

I refer to the above event merely to illustrate my toil within the "*problem formulation*" stage of ADR. While Sein et al. (2011) outline this as the first stage in ADR, they unfortunately do not refer to "*how*" one might/should go about "*problem formulation*". I, probably like many other before me, ran into the solution space, convinced that I understood "*the problem"* that needed to be solved. I really thought after the presentation *on "Tragic Thursday*" that I was the issue, that I may not be the patient/researcher for the job in hand. So, was it just me?

Well yes and no. Let me clarify. As the earlier background section on "*problem formulation*" exemplifies there is a lot more to "*problem formulation*" than one might initially think. Unsurprisingly, as we saw, we humans are not always logical in how we approach problems, we hold many biases and repeatedly make suppositions, becoming fixated on unjustifiable assumptions (Weisberg & Alba, 1981). These faults within humans of course run counter to the successes that we strive to achieve, to the challenges that we strive to overcome.

Furthermore, solution fixation often results in leading to adverse consequences, precluding/hindering in-depth questioning or interrogation of problems, and prematurely freezing a problem space before it can fully form. I think the most unfortunate negative effect of poor "*problem formulation*" is on the divergent exploration of creative possibility in design. I was an exemplar of this behaviour. As a patient living with CF for 48 years, with countless visits to doctors, I thought I knew the problem "*inside out*". As far as I was concerned, I had conducted an initial survey of 305 respiratory patients/parents back in 2015, and 78% said they

had difficulty in remembering their medical history. Furthermore, over 95% of them said they would use a secure app if one existed. I had taken offense to being challenged. I remember thinking "*what the hell does he know?"* My ego had thwarted my ability to hear and appreciate the very sound advice that was actually being imparted to me.

Thankfully, I'm not a stubborn fellow and sense prevailed. I have since become a lot humbler and more open to criticism. I suppose, as a patient who has faced the question of my mortality at a very young age, I have become somewhat resilient, accustomed to picking myself up, dusting myself down (this often involves giving myself a good telling off, including the words – "*stop feeling sorry for yourself, remember why and who you are doing this for*"), and getting on with it. After all, someone had to resolve the issue, and if not me then who?

Moreover, had *"Tragic Thursday"* not happened, I would be sitting here on this Saturday afternoon in February 2020 (like many others before me) with a failed app. I most definitely would not be boxing up a solution for departure to the Royal London Children's Hospital, London. A solution that in the weeks ahead will grace the laps of carers all-over south-east England *within* their real-world medical appointments.

Now What?

As we established earlier, I was not alone in my thoughts and tribulations regarding "*problem formulation*". Mullarkey & Hevner (2018) and others had also reported complications with this stage of ADR. My challenge then, was to be mindful of the real need for an in-depth implicit problem analysis and to understand and define the

information problem that CF patients/carers face *within* their medical appointment in tandem with a solution/s to ameliorate same. My next design workshop was calling.

My lesson learned was:

L1. If we wish to achieve successful outcomes, "*Problem formulation" requires a conscientious focus on problem comprehension, avoiding "solution fixation" and other assumptions.*

2.5.3. Vignette 2: So, what's the problem again? - September 2016

What happened?

I was sitting in the car in mid-September 2016, on my way to a workshop and looking forward to working with my design team. I was excited but also extremely nervous; it was only a week ago that my ship (I call the patient innovator) had taken a flurry of shots across the bow and nearly sunk, joining all the other vessels who had failed to survive on the wicked high seas in the world of innovation.

Many thoughts had been incubating in my head since "*Tragic Thursday*". My metacognitive processes were working furiously, my thoughts were a mix of emotions and ideas; to anyone brave enough to look inside my head, it would look "*really messy*", like my room when I was a kid. I replayed the many medical appointments that I had attended in my mind, in tandem with all the literature that I had read in the area since Autumn 2014. While I had identified a problem or anomaly in the medical appointment, the issue that I now endeavoured to solve was to understand and define the problem that CF patients/carers face *within* their

medical appointment, and delineate it in a way that made sense to me and others. Suddenly a memory popped into my mind, vis-à-vis the time I endeavoured to explain the issue to my darling wife for ten minutes or more, after which she turned around and said "*so, what's the problem again?"* Moreover, I needed to be able to classify and represent the problem in a way/s that would assist me and my design team to see how we might best deal with it.

I was struggling; my experiences as a CF patient alone were not sufficient to articulate and solve the problem. I felt as if my mind was constantly being polluted by irrelevant details and assumptions. I could feel my heart beating faster, questions flooded my mind, how was I going to structure/represent the problem? How broad was the problem? What were the constraints? What knowledge was needed to understand it and solve it, and what gaps existed in my/our current knowledge base? What external and social factors would come into play? What strategy would we adopt? What did success look like? It was going to be a thought-provoking, challenging workshop!

So What?

Let's be honest; we all face problems of one kind or another every day of our lives. A one-year-old may face the problem of how to stand unaided, or how to escape from their cot, the Alcatraz of their world. Teenagers on the other hand face the challenge of living in the evolving world of social media, acceptance, bullying and so on. Problems come in all forms, some are simple, some are quite complex in nature and others have an undeniably *"wicked"* composition.

While there is a myriad of difficulties *within* the medical appointment, I needed clarity regarding the specific enigma (or part thereof) that I was going to focus on. I needed to avoid or at least be aware of the symptoms that were polluting and confusing the situation I was trying to remedy. Those related to other problems and yet overlapped with mine, otherwise my ability to make sense of the issue with my design team was going to be a long arduous process, one which would most likely end in failure. My design team and I needed to find an appropriate representation of the problem we had identified *within* the medical appointment, one that would give us insight/s to an appropriate solution pathway. While my experience was beneficial and useful, it was one CF patients' voyage and nothing more. There were many more CF patients/carers that also had their story to tell, stories that would enrich our comprehension of the problem space. But how should I go about gathering such insights?

The problem I found with the ADR methodology is two-fold; firstly, it appears to hold a rather technocentric view of innovation, by this I mean it does not seem to take into account the often-idiosyncratic nature of humans. This is evident in the lack of guidance on "*how"* we might/should come to truly understand the people behind a problem. For example, who has the problem? Why is it a problem? What do they think? What really matters to them? What do they feel, as they toil within a problem space? and so on. The ability to garner such fundamental human insights are crucial to disentangling, understanding and defining a problem. Secondly, not enough emphasis seems to be placed on the "*problem formulation*" stage of ADR. It's almost portrayed as if "*problem formulation"* is a straightforward process, when in reality the opposite is often true; it's frequently wicked and ill defined.

Now What?

Arlin (1990) argues that for a problem to be real, there needs to be a "*felt need*" to eradicate any impediments to an objective. Considering these words further, they conjure or evoke thoughts of sentiment, of emotions, the very essence of what makes us human. Therefore, to pursue ADR within the context of the social environment of the medical appointment, I also needed a deeply human-centred mindset, an approach that was profoundly human in and of itself. Unfortunately, I found ADR wanting in this regard.

In contrast, Design Thinking focuses on a user's experiences, and the emotions that are encapsulated in such events. Design Thinking is a human-centred design methodology that "*relies on our ability to be intuitive, to recognize patterns, to construct ideas that have emotional meaning as well as functionality, to express ourselves in media other than words or symbols"* (Brown, 2019, p.12). As one might imagine some of the core principles of Design Thinking are empathy with users and a discipline of prototyping.

Emotions are an integral part of what makes us human. And so, my design team and I began a series of Design Thinking workshops, beginning with a number of Design Thinking tools, from personas (Appendix G) to empathy maps (Appendix F), and journey maps (Appendix H & I). This meant spending a great deal of time with fellow CF patients and carers discussing the many facets of living with CF, their experiences (building on mine) *within* the medical appointment, capturing their reality of being a CF patient or having a CF child, unique perspectives that

were both profound and deeply insightful and oftentimes quite moving. Empathy became the key to helping define the problem, but why empathy?

Many different interpretations of empathy exist from sharing others' feelings and comprehending others' emotions (Abram et al., 2017; Buffel du Vaure et al., 2017; Fan et al., 2011; Groen et al., 2013) to feeling what another experiences and capability to appreciate others' views (Crijns et al., 2017). While we shared a medical condition, our life journeys are our own, unique, moulding us and shaping us into individuals. I came to understand the experiences of other CF patients/carers, assisting me to feel what they felt. I came to comprehend the stress they experienced living with CF, something that they (and I) have learned to manage on a daily basis. I heard of their experiences of holding a conversation with doctors whilst being short of breath, described by one adult CF patient: "*I was gasping for air, and trying to remember stuff for the doctor"*. A young mother of a CF child explained to me what it was like trying to list the medications that her child was on at a particular medical appointment, "*my 5-year-old child was really sick with a chest infection, she was crying due to the pain in her lungs, it was impossible to concentrate, it felt like I had 500 things going through my head, I was so stressed. I remember thinking, what if I make a mistake? What if I leave something out? I felt so guilty and helpless at that moment."* While insightful, I confess that at times I found this aspect of the project very difficult from a personal perspective. However, I learned to manage my own feeling quite quickly, forcing myself to compartmentalise my thoughts and feelings when and as required. I knew that this was critical if I wished to succeed and avoid floundering on the rocks in the sea of my own internal thoughts and emotions.

Nevertheless, it's important to note that it was through this appreciation of the problem through the senses and experiences reported by other patients/carers, that we (my design team and I) would come to realize that a techno-centric approach to the problem was not an appropriate start point. It was only by really listening to what the patients/carers were telling us, that we came to grasp what we were really dealing with. They were not in fact talking about apps or technology at all, they were complaining about their needs regarding their information. Their frustrations regarding access to their medical history when and as required. One patient explained; *"If I'm away traveling, I need to have my medical information at hand in case I get sick. I can't walk into a doctor who knows nothing about me or my condition. This happened to me before and I was put on the wrong treatment. It was very upsetting; I could have died."*

My design team and I eventually settled on the following new problem statement:

"CF patients/carers are not having their information needs adequately addressed within their medical appointments".

Interestingly, renowned cardiologist Eric Topol argued that "*patients exist in a world of insufficient data, insufficient time, insufficient context"* (Topal, 2019, p.280). In line with the principles of Design Thinking, we decided to engage in pretotyping (paper-based prototyping) in the form of a check list, to aid in our comprehension of initial interest and actual usage by users of our solution. The pretotype was designed for CF patients/carers to fill out *before* and *during* the doctor's appointment. Pretotyping (conceived by Alberto Savoia, 2011) also made sense as it enabled the smallest investment of time and money possible, whilst still

facilitating the capture of distinctive insights from users of the check list within the context of the medical appointment. The check list pretotype was also prudent as a precursor to any digital solution that we may eventually embark on. It also steered me clear of "*falling in love*" with any early solutions. I wished to avoid another Tragic Thursday. Check list iteration one was designed and released at the end of September 2016 (Appendix E) with evaluations conducted at the end of October and through November 2016 (Appendix D). Interestingly, even at this early stage, the check list was demonstrating positive outcomes, with 81% of participants reporting better memory recall as a result of using the check list.

My lesson learned was:

L2. "*Problem Formulation" requires in-depth human centric exploration - scrutinizing a problem thoroughly through the senses of those who experience it, understanding how it affects them, culminating in the articulation of an accurate problem definition and more positive solution outcomes.*

2.5.4. Vignette 3: Teaching an old dog new tricks - May 2017

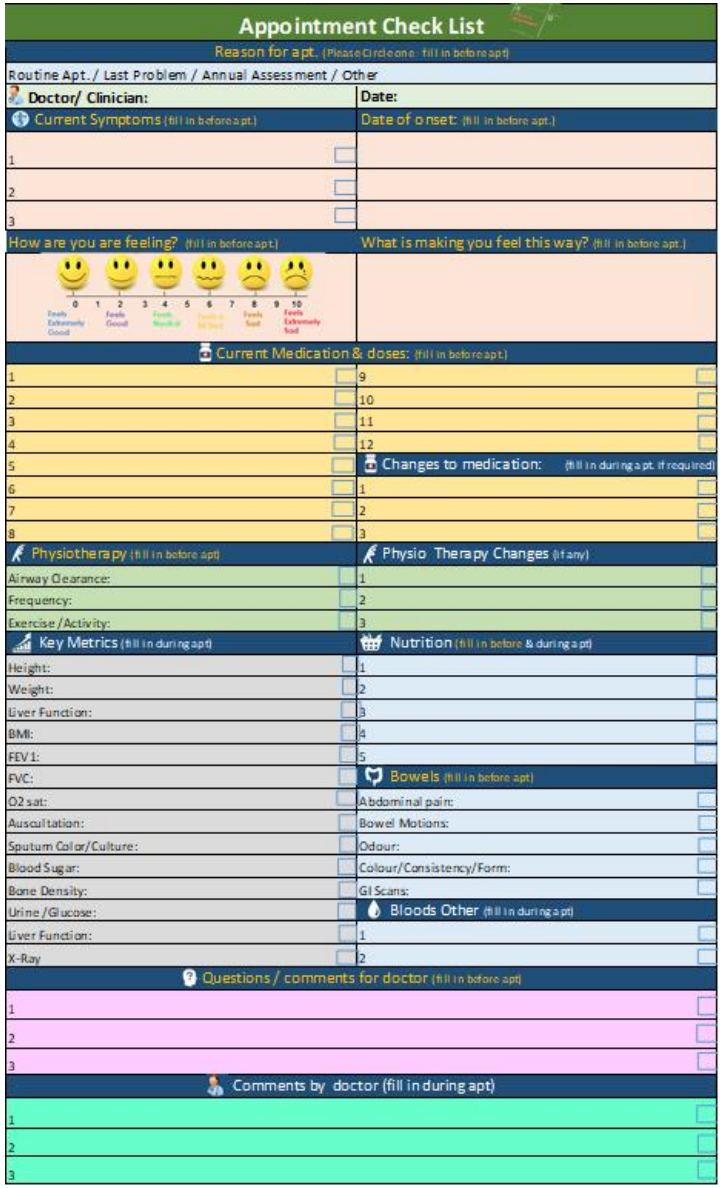
What happened?

It was a beautiful morning in May 2017, I was out walking my dog Suzy down in the local forest not far from home. There was a very light breeze, and the trees gently swayed to the dawn chorus of bird acoustics, a melody of song and calls. I had recently completed iteration three (Figure 2-5) of the check list and thankfully the evaluations were very positive (Appendix D), with the artefact having major impacts within the CF community. Here patients/carers reported reduced stress and

increased empowerment as a result of having their medical information with them *within* their medical appointments, and of course afterwards. The check list really appeared to work, but why was it working so well?

What had we done that seemed to be tipping the results in our favour? Our enhanced understanding of the problem definitely seemed to be manifesting itself in the delivery of an improved solution. However, I had this innate feeling that I was missing something, that we still had not achieved an absolute sense of why the check list was so impactful? I was bothered.

I proceeded down the forest path toward this small brook that my dog was playing in. She was playacting with a stick, when much to her dismay she dropped it and it disappeared into some sort of small drain. I watched her with as much a sense of curiosity as amusement, as she endeavoured to retrieve her prized possession. She approached the drain from one angle, then another, and then back again.



Appointment Check List

Reason for apt. (Please Circle one - fill in before apt)

Routine Apt. / Last Problem / Annual Assessment / Other

Doctor/ Clinician:	Date:
Current Symptoms (fill in before apt.)	Date of onset: (fill in before apt.)
1	
2	
3	
How are you are feeling? (fill in before apt.)	What is making you feel this way? (fill in before apt.)
0 1 2 3 4 5 6 7 8 9 10	

Current Medication & doses: (fill in before apt.)		Changes to medication: (fill in during apt. if required)	
1	9	1	
2	10	2	
3	11	3	
4	12		
5			
6			
7			
8			

Physiotherapy (fill in before apt)	Physio Therapy Changes (if any)
Airway Clearance:	1
Frequency:	2
Exercise /Activity:	3

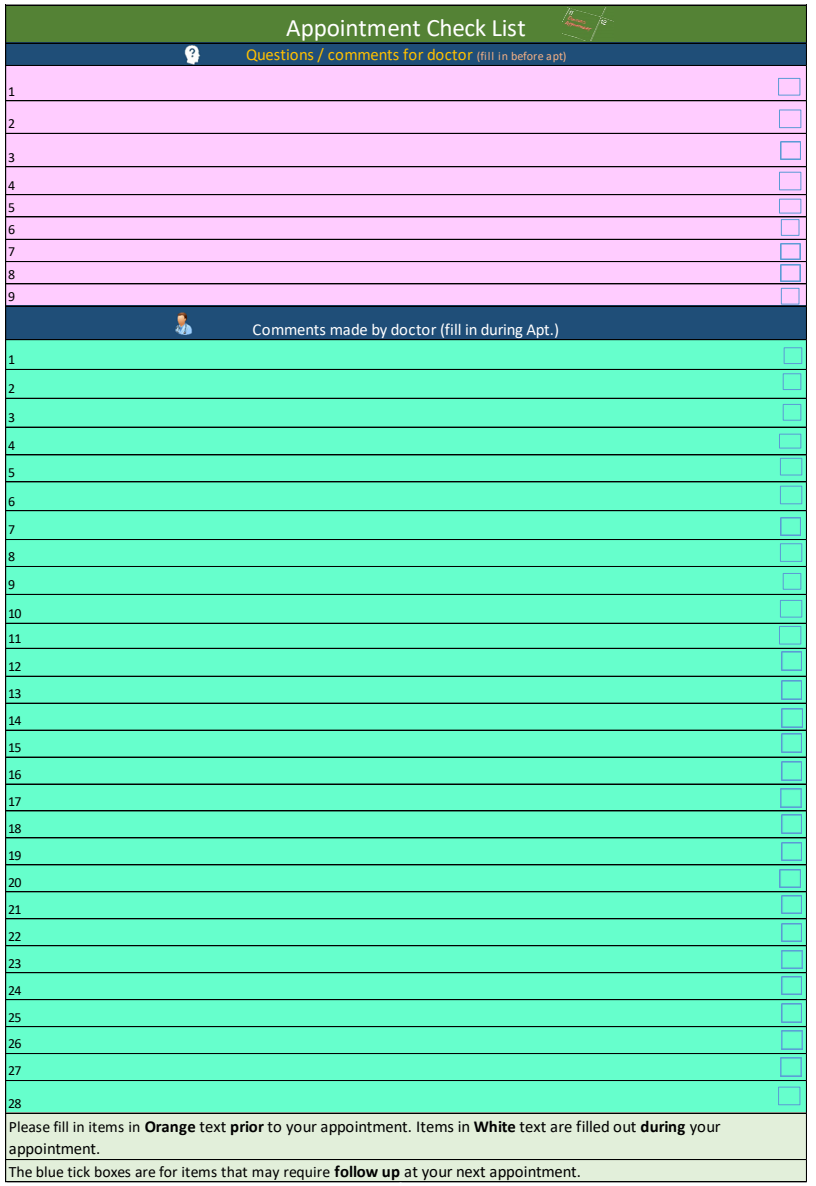
Key Metrics (fill in during apt)	Nutrition (fill in before & during apt)
Height:	1
Weight:	2
Liver Function:	3
BMI:	4
FEV1:	5
FVC:	Bowels (fill in before apt)
O2 sat:	Abdominal pain:
Auscultation:	Bowel Motions:
Sputum Color/Culture:	Odour:
Blood Sugar:	Colour/Consistency/Form:
Bone Density:	GI Scans:
Urine /Glucose:	Bloods Other (fill in during apt)
Liver Function:	1
X-Ray	2

Questions / comments for doctor (fill in before apt)

1
2
3

Comments by doctor (fill in during apt)

1
2
3



Appointment Check List

Questions / comments for doctor (fill in before apt)

1
2
3
4
5
6
7
8
9

Comments made by doctor (fill in during Apt.)

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
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28

Please fill in items in **Orange** text **prior** to your appointment. Items in **White** text are filled out **during** your appointment.

The blue tick boxes are for items that may require **follow up** at your next appointment.

Figure 2-5 Version Three of Check List

This all went on for a number of minutes; it was clear by her expression that she was engaging the very limits of her cognitive abilities, as she tried to make sense of the predicament. Eventually, she managed to work it out, after several failed attempts doing it one way, she suddenly approached the problem differently, in a simpler fashion, and she had her stick again!

My mind wandered back to my own thoughts, was there other ways that I should be tackling/viewing the information challenges that CF patients/carers were experiencing as well? Surely there were additional ways from which I could view the problem/solution, possibilities yet to be considered, ways that may come to enlighten me as to why the check list was begetting such light into the often-challenging setting of the medical appointment. I was convinced there was more to learn, more to understand and yet every time I tried to think about it, I found myself back where I started. It was like a neural impasse, as if the mental pathways in my mind were predetermined, immovable objects, defeating my abilities to explore new possibilities, new ways of thinking. I grew frustrated, my mind was tiring. I kicked a stone into the brook, "*if only we had a more advanced memory, akin to some sort of futuristic form of AI, then there wouldn't be this stupid problem"* I thought. And then just like my dog a few moments earlier, a new thought entered my mind, "*If we had perfect memories, we would not need a solution*".

The problem I thought, was not really "*information needs*" so much as the limitations of human memory, arguably defective, often resulting in an inability to remember, a failure to recall memories on demand, a malfunction of our biological information retrieval system. Inadequate "*memory recall*" was the real problem, it

had been there under my nose all the time, and yet I failed to see it, until now, months later.

So What?

The above vignette reminds me of the American inventor and engineer Charles Kettering when he declared that "*a problem well stated is a problem half-solved"* (Maclean, 2005, p.53). So, what exactly did Kettering mean here? Do we take from his statement that once a problem is stated that we are halfway to a solution? Or does he infer something more arcane, that even with a well stated problem, there is abundant knowledge yet to be unearthed, comprehended, and considered, regarding how and why solutions perform as they do within their intended environments? Having travelled through my ADR experience I think he may well have intended for us to appreciate both in combination and individually.

In May 2017, I really realised and appreciated the richness of looking at a problem through multiple lens. I was also amazed at how static my cognitive frameworks or schemas were. Moreover, I was amazed at how long I had stayed in these cognitive states, unable to move, paralysed if you will, this despite numerous evaluation interviews with patients/carers and workshops with my design team. Why had it taken so long for the older mental model to be replaced/augmented with a new one that would enhance my explanatory power? Was it the assumptions I was making whilst trying to make sense of the complex environment of the medical appointment? Had I become locked in on a particular mental representation of what I perceived was the "*sweet spot*" of the issue?

I mentioned earlier that "*what we understand and how we understand a situation depends on the information we bring to a given situation, and the longer we think about the situation the more its cognitive representation changes. It may be assumed that cognitive elaboration activates more schemata*" (Aaltonen, 2016, p.29]. I was fascinated by this and yet cautious, what other points of view had I not considered? In spite of these contemplations, I decided I would refrain from tormenting myself, and spoiling this moment in the process.

I had no doubt that as I continued on my voyage, I would discover new ways of thinking, of framing my understanding. However, a sense of balance and perspective is required, one must avoid entering a state of "*analysis paralysis*". As the esteemed English writer Samuel Johnson once said, "*nothing will ever be attempted if all possible objections must first be overcome*". I would take each enlightenment as it came, relishing the cognitive challenge that each schema would bring.

More than one account of a complex system is achievable, where altered portrayals will break the system down in diverse forms and changed descriptions may also have altered levels of intricacy. I was both relieved and excited that I had discovered a new viewpoint from which to perch my telescope of inquiry. Moreover, I felt an augmented confidence ignite within me, the cause of which was twofold; firstly, I now felt more assured regarding my grasp of the actual problem, and secondly, I sensed more confidence in my appreciation as to why the check list was functioning so well for CF patients/carers.

Now What?

I relayed my thoughts to my design team, and we came up with a new problem statement.

"The challenges of memory recall/Information retrieval that CF patients/carers have/experience within the medical appointment are not well understood or solved".

This made a lot more sense to all of us, and so taking a People, Process, Technology, Data view we created a model (Figure 2-6) to depict our new representation/understanding of the problem including the roles of memory recall/information retrieval *within* two key information stages of the medical appointment. I have also expanded on each of these People, Process, Technology, Data concepts as they pertain to the medical appointment in Table 2-3. The usefulness of Figure 2-6 and Table 2-3 is twofold, first to depict my interpretation of the problem, and secondly, to highlight the advancement of my comprehension of the various interacting/moving components within the problem space.

Moreover, I came to realise why the check list was so effective, it was in effect acting as a tool aiding the long-term declarative memory of the patient/carer *within* their medical appointments. Looked at from another perspective, one could say that it achieved this by actually relying less on the patient's/carer's own memory and more on the check list *within* the appointment. Patients/carers now came prepared with the information required *within* the *elicitation* phase of the medical appointment already written down in front of them. Moreover, they had a placeholder to capture the key information *within* the appointment as well.

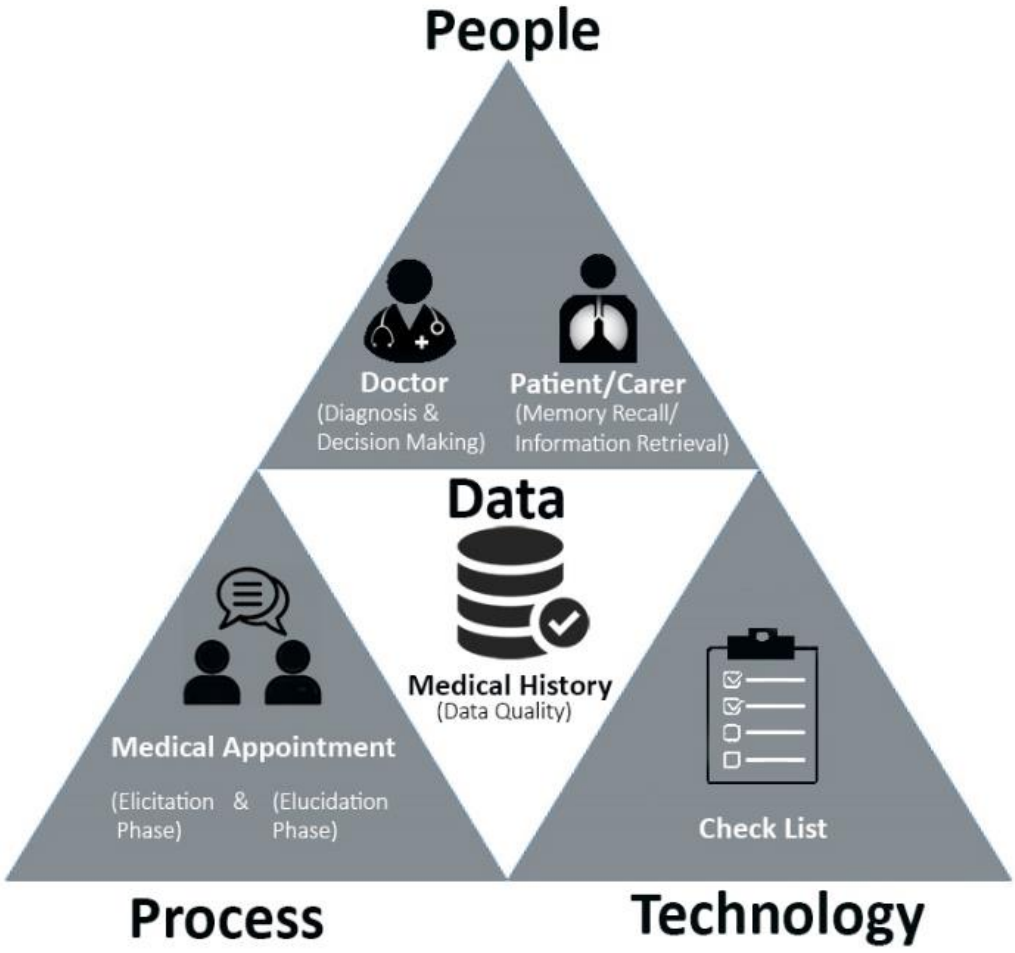


Figure 2-6 People, Process, Technology, Data

Hence, they would not need to rely on memory when they left the medical encounter either, they had it all in the check list and could refer back to it as required, even when traveling, if they happened to get ill. It probably comes as no surprise then, why patients/carers were reporting such impacts on stress and empowerment. Additionally, I really came to fathom the potency of precise "*problem formulation*" vis-à-vis its impacts on actual outcomes.

Table 2-3 People, Process, Technology, Data model concepts

Concept	Reference
People	
Doctor	
The purpose of the medical appointment is to *"make the diagnosis"*.	Lazare, 1995
The consequences of poor memory recall/information retrieval: 1) Quality of information imparted to a doctor. 2) Ability to make effective diagnosis and treatment decisions. 3) Impacts on patient outcomes.	Cohen et al., 1995
4) Clinician satisfaction	Schraa et al., 1982
Patient/Carer	
Research shows *"that memory for medical history, like other forms of autobiographical memory, is likely to be flawed, incomplete and erroneous"*.	Cohen et al., 1995, p.273
Process	
The Elicitation Phase	
Doctor and patient/carer participate in a bi-directional conversation regarding the patients' medical history, current wellbeing, current medication and so on.	Sarkar et al., 2011
Furnishes the doctor with 60-80 percent of the data required to make a diagnosis.	Hampton et al., 1975; Sandler et al., 1980; Kassirer, 1983
The Elucidation Phase	
Doctors communicate diagnoses, clinical options, self-care plans, in tandem with overall advice regarding the management of a medical condition/s.	Martin et al., 2014
This phase directly impacts patient adherence and other self-managing activities, such as regime change.	Mc Pherson et al., 2008
Technology	
Check List	
Defined as "*a formal list used to identify, schedule, compare or verify a group of elements or . . . used as a visual or oral aid that enables the user to overcome the limitations of human memory".*	[The Federal Aviation Administration, 2016, p.1]
Data	
Medical history data includes: 1) Medical appointments 2) Symptoms 3) Illness episodes 4) Encounters with other clinicians 5) Medical therapies 6) Medications.	Cohen et al., 1995

However, as one might expect, as I delved deeper into the area of memory recall *within* the medical appointment, I realised there was a lot more to this puzzle than I first envisaged or ever imagined on that beautiful Summer morning in May 2017.

My lesson learned was:

L3. *In the "problem formulation" stage of ADR, we must challenge ourselves to look at a problem from different perspectives, from alternative disciplines, if we haven't found/considered alternative viewpoints, we may well fail to understand a problem well enough, affecting the most appropriate articulation of the problem definition, and the successful design of a solution, or comprehension of why a solution functions as it does.*

2.5.5. Vignette 4: Breaking it down - May 2018

What happened?

It was the 25th May 2018, a warm humid day, the sky was cloud-flecked, and the various birdsongs bestowed a pleasing accompaniment to the day. I was on my way into a symposium in my University to give a presentation on my research. I was nervous, my stomach was making noises, clamouring's that I hoped were inaudible to the various scholars gathered in the room. I imagined none would be too fond of hearing such clamouring's ascend from my abdomen.

I hoped they would however be very interested in hearing how the check list we had designed, built and evaluated, functioned so well *within* the environment of the CF medical appointment. Moreover, following a nine-month rigorous systematic literature review of memory recall *within* the medical appointment. I sought to

impart where my comprehension of the problem had advanced to, and why carrying out such an activity was fundamental to unlocking the additional knowledge I required in the "*problem formulation*" stage of our ADR project.

So What?

I had decided to do the meticulous literature review for two reasons, firstly I wanted to understand why the check list was functioning so well in the medical appointment, secondly, I wanted to see if I was overlooking anything, for example was defining the problem as memory recall/information retrieval of CF patients/carers *within* the medical appointment comprehensive/deep enough? I found that the answers to both questions were in fact deeply intertwined.

In the first instance I came to understand that human declarative long-term memory was analogous to many complex systems consisting of components, in this case different memory types: episodic memory, autobiographical memory and prospective memory etc. (Appendix J). The components themselves are often simple (or can at least in this instance can be viewed as such) and interact with each other with various routes possible amongst components, mediated in distinct circumstances.

So why was the check list functioning so well in the medical appointment? Henry Ford is noted for saying "*Nothing is particularly hard if you divide it into small jobs*". Breaking down memory recall/ information retrieval into its components, studying the doctor patient narratives (supplied by consenting patients/carers from real medical appointments) and assigning declarative memory components to each sentence or group of sentences allowed me to unearth a more profound

comprehension of the complexities of dialogues *within* the medical appointment and the variety of long-term declarative memory components used therein. Furthermore, it exposed the pressures that memory recall places on the patient/carer, such as recalling a particular episode (episodic memory), time period/s (autobiographical memory), or remembering to report symptoms at an appointment (prospective memory) or a combination of declarative memory types. Additionally, I found that the check list design actually maps to "*aid*" the declarative long-term memory component drawn upon by the patient/carer *within* the medical appointment. This deeper, more comprehensive level of understanding of memory recall/information retrieval, where I broke it down into its components, afforded me a far deeper knowledge from which to view, examine and indeed make sense of the problem I endeavoured to solve, and of course as already put forward, why the check list functioned so well for CF patients/carers *within* the complexities of the medical appointment.

Secondly, while a single check list simplifies the capture of information at a particular medical appointment, and so aids the episodic memory of the patient/carer regarding that specific event, I came to understand that from an autobiographical memory perspective the check list was still somewhat inadequate. I wanted to support a patients'/carers' autobiographical memory in the best way possible, and while theoretically one could file away a single printed check list in a folder *after* each medical appointment, I decided that this would not suffice. Patients/carers have enough going on in their lives without trying to find another workaround. Being a patient myself, I was sick to death of always having to settle for second rate solutions, solutions that I would later have to adapt to my own needs.

On several occasions I remember thinking why is it that no one can get this stuff right? Are we (patients) that hard to understand, are our needs that difficult? Or is it that no one really gives genuine thought when designing products for us? I could not be a hypocrite, I had to improve the check list, no workarounds!

Now What?

Firstly, my design team and I came up with a new problem statement.

"*The challenges of memory recall Information retrieval (and its components) that CF patients/carers have/experience within the medical appointment are not well understood or solved".*

Secondly, after iteration 3, and my comprehension of long-term declarative memory components, we decided to create a professional, physically robust booklet (Figure 2-7), with a little help from a professional graphic designer (a friend of mine) (see Appendix K for the final check list). The booklet contains 28 check lists and unshackles the patient/carer from having to do any workarounds, including any printing. At once, a repository of medical discourse is created, where 28 medical appointments check lists are held together, not only facilitating the patients'/carers' episodic memory and prospective memory, but also acting as an autobiographical memory of a specific timespan. Searching for a previous appointment/s was now simple and straightforward.

Many may argue that this further exploration was a step too far, unnecessary, and indeed prohibitive for many researchers/organisations in terms of cost, etc. While I appreciate these sentiments, I would not agree. If you really care about the user's

experience (and you should) and you want to deliver quality impactful solutions, you must be willing to "*go the whole nine yards*". In fact, I believe this is the only way to accomplishing truly successful outcomes. To do anything else is to cheat yourself, your organisation and most importantly the user from what might have been.

Figure 2-7 The Check List Booklet

Had I not gone deeper, the check list as a booklet would never have come to pass. Granted I would have a check list (as a single page); however, I cannot say I would be confident that a patient/carer would continue to go to the trouble of printing a check list *before* every appointment, and then file it away afterwards. One must appreciate that chronic patients/carers are busy trying to lead as normal a life as possible and they often have very complex and time-consuming treatment schedules. Hence, asking what may seem a simple task, can unfortunately often be the "*straw that breaks the camel's back*" for a patient/carer, and hence lead to

unused/underused solutions. By having a deeper grasp of the problem, I was able to put this knowledge to good use, advancing to a more robust solution. This I believe is why so many are now requesting the check list booklet.

Additionally, when I explain the rationale behind the workings of the check list booklet to those with the CF community, including clinicians etc. I can see that they are really intrigued, and if I may be so bold as to say, excited by the solution. This has of late manifested itself in a large amount of dialogue within the community, much of which I am only now becoming aware of, as it has translated into invitations to various clinical conferences, and international requests to see the check list booklet, and of course boxes of check list booklets being taped up on a Saturday afternoon. Check list booklets that will soon find their way into the hands of CF patients/carers far and wide.

My lesson learned was:

L.4 *Going deeper in the "problem formulation" stage of ADR, will help to explain observed phenomena, highlight shortcomings in a solution, enrich problem definitions, resulting in a truly comprehensive understanding of a problem domain and the delivery of truly successful impactful solutions.*

2.6. Concluding Remarks

Unfortunately, that a small amount is appreciated vis-à-vis how problems are formulated in ADR seems as true today as it was six decades ago. In many of the ADR papers that I have read, there appears to be a very quick shift in focus to the subsequent stages of the methodology, with little mention/focus on the "*problem*

formulation" stage. Moreover, *"problem formulation*" is seldom mentioned again in manuscripts, this despite the iterative nature of ADR (Figure 2-1), where after "*reflecting and learning*" the researcher/s refer back to the "*problem formation*" stage in order to ascertain whether or not a problem definition has changed or evolved. This is of course not to say that the stages that follow the "*problem formulation*" stage are not important, quite the contrary, they are also fundamental to an ADR project. Hence, I have included same again in Figure 2-8 below, which unlike Figure 2-4 earlier, now includes the lessons learned (as concepts) from each vignette extracted from my ADR journey. You will note in Figure 2-8 that our impactful outcomes are only attained at the culmination of our journey, through iterations of ADR and *"problem formulation"* exploration and determination.

The question that I still contemplate is why more regard is not given to this crucial stage of ADR? In my researcher story overlaid on an ADR story I have bought to bear (through my series of vignettes) how difficult this stage of ADR actually is, what can go wrong without a conscientious focus on problem comprehension, and yet how beneficial time spent in this stage of ADR is, in terms of research impacts and results. Surely, I'm not alone in my struggles as a researcher in "*problem formulation*"?

As I have already stated, but wish to emphasise once more, it is fundamental to empathise/understand the people behind a problem, what they experience, what they are feeling, and what and how they think, if you wish to deliver truly impactful solutions and sought-after outcomes. Indeed, Southard was the first to articulate the significance of empathy in the doctor patient therapeutic relationship and its role in

assisting diagnostic ("*problem formulation*" *within* the medical appointment) outcomes (Southard, 1918). To do otherwise is to deny our humanity, blocking the very comprehension we require to address the often-difficult problems we encounter, as we go about our lives on a daily basis, navigating the many complex systems within which we live.

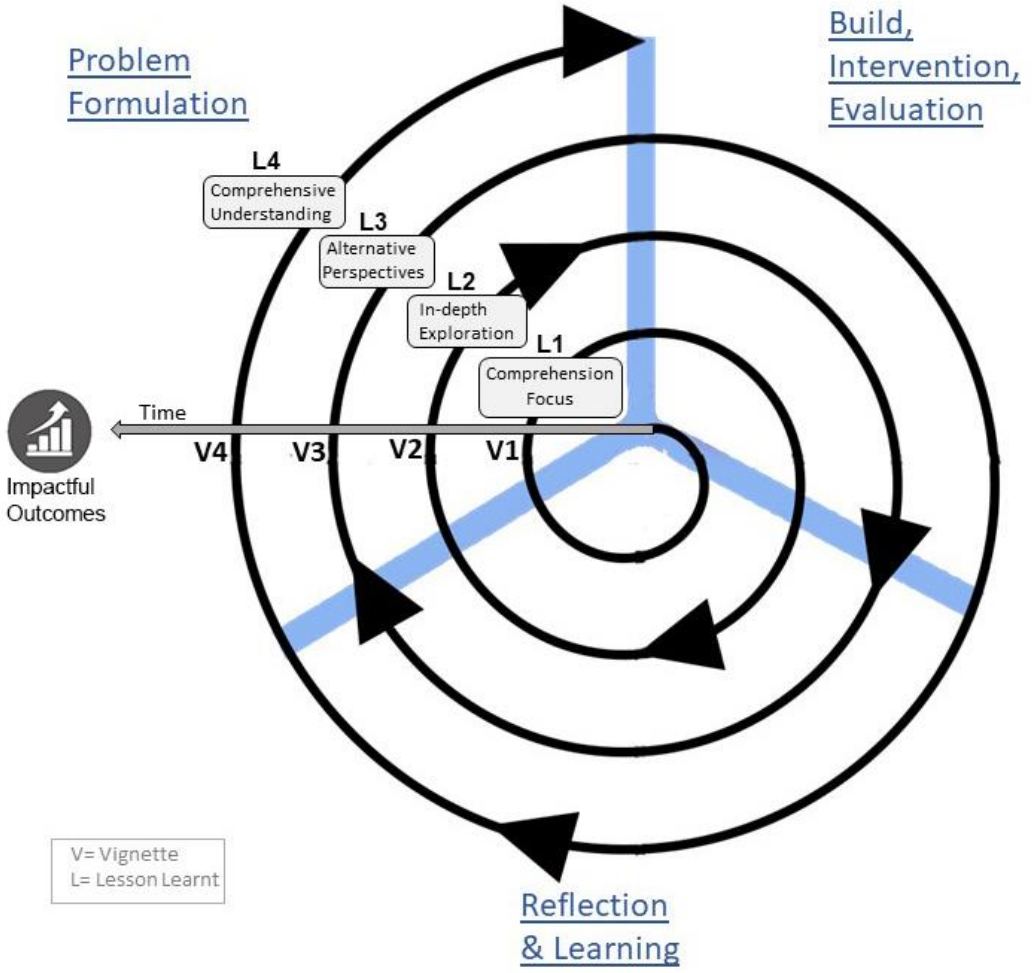


Figure 2-8 Visualisation of reflection within the context of the ADR project

In Vignette 3, I contended that we challenge ourselves to look at a problem from different perspectives, to be more open to other disciplines and to be prepared to "*repeatedly change our point of view, our way of looking at the problem. We have to shift our position again and again*" (Polya, 1957). This augmented

comprehension not only facilitates a more appropriate articulation of a problem but should also liberate insights into why a solution functions the way it does within a particular environment.

However, as L.4 illustrates, we must also be willing to probe and dissect these new viewpoints further, atomising them down into components/concepts, facilitating deeper insights into phenomena, deepening our problem definitions, and thereby enabling a truly inclusive augmented comprehension of a problem. Additionally, such curiosity draws our attention to inadequacies in our solution/s, such as the check list prior to it being in booklet form, where it really failed to address autobiographical memory. Through this knowledge, we enhanced the check list further. Without delving deeper this would not have happened.

The check list produced evolved and was shaped, not merely by the environment into which it was placed, but also by my mind, which also underwent a type of metamorphosis, as empirical findings and knowledge waltzed together to the beat of my heart and the passions and conviction that expounded from within. Time and time again on this ADR project, I felt like I was on a journey of self-discovery, with many twists and turns, good days and bad days, days that taught me some valuable lessons, experiences that sometimes had a real sting to them, but won't be forgotten.

None of it was of course in vain, quite the contrary, I know I have made a real difference and continue to change the lives of many CF patients/carers *within* their medical appointments. I could not ask for a better outcome to my research endeavours. As pointed out earlier, I put this down to both grit and determination, especially as I have shown, within the "*problem formulation*" stage of my research.

Therefore, fundamental to ADR success is the continuous revisiting of "*problem formulation"* after each iteration of an artefact, it is only by doing same that we can hope to gain a truly augmented understanding of a problem, and become more confident in designing, and in our solution designs. I hope what I have discovered and aimed to impart here, proves useful/insightful to those who brave the high seas of *"problem formulation"* in ADR, helping them to avoid some of the fatuous mistakes that I have made whilst on this chapter of my ADR voyage. Helping them reach their intended research destination safe and sound, assured that they too, have delivered impactful solutions through an augmentation of problem comprehension.

In tandem with the above, I would advocate for the inclusion and portrayal of the actual realities of this stage (as I have endeavoured to accomplish in this reflection) to be included and explored by researchers and practitioners. I feel that the insights garnered regarding same would not only bring a sense of realism and humanity to research (a component that I feel is often missing), they would also generate contributions to knowledge in and of themselves, the "*how to*" or "*how I/we*" navigated challenges encountered in research.

I miss my dear sister, but I choose to honour her memory by doing something that I know would bring a warm smile to her face. I will be honest at this moment I have no idea where my researcher voyage will eventually take me, but it feels so right. Like a faint whispering in my ear that gets louder each day, like a fog lifting, giving a clearer aspect to the road ahead. My heart quickens as my quest becomes clearer.

2.7. References

Aaltonen M. (2016). *The Third Lens. Routledge*. Taylor & Francis.

Abram, S. V., Wisner, K. M., Fox, J. M., Barch, D. M., Wang, L., Csemansky, J. G., Smith, M. J. (2017). Frontotemporal connectivity predicts cognitive empathy deficits and experiential negative symptoms in schizophrenia. *Human Brain Mapping*, 38, 1111–1124.

Ackoff RL (1956). The development of operations research as a science. *Oper Res* 4(3):265–295.

Ågerfalk, P. J. (2010). Getting pragmatic. *European Journal of Information Systems*, 19(3), 251–256.

Anderson L. (2016) Analytic autoethnography. *J Contemp Ethnogr*. 35(4):373-395.

Arlin, P. K. (1990). *Wisdom: The Art of Problem Finding*. Cambridge, MA: Cambridge University Press.

Basadur, M. (2004). Leading others to think innovatively together: Creative leadership. *The Leadership Quarterly*. 15. 103-121.

Baskerville, R. & Wood-Harper. (1998). Diversity in information systems action research methods. *A. Eur J Inf Syst*. 7: 90.

Berthon, P., Pitt, L., & Morris, M. (1998). "The Impact of Individual and Organizational Factors on Problem Perception: Theory and Empirical Evidence from the Marketing-Technical Dyad," *Journal of Business Research* (42:1), 1998, pp. 25-38.

Boud, D., Keogh, R., Walker D. (1985). *Turning Experience into Learning*. Kogan Page. London.

Bretschneider, U, Hartmann, M., Leimeister, J. (2015). Fostering Ideation Among Patients: Exaptation of Web-based Ideation Platforms as Health 2.0 Tools for Virtual Patient Communities Completed Research Paper. *Thirty Sixth International Conference on Information Systems*, Fort Worth.

Brody, R., (1982). *Problem Solving, Human Science* Press, New York.

Brown T., (2019). *Change by design*, Harper Business.

Buffel du Vaure, C., Lemogne, C., Bunge, L., Catu-Pinault, A., Hoertel, N., Ghasarossian, C., Jaury, P. (2017). Promoting empathy among medical students: A two-side randomized controlled study. *Journal of Psychosomatic Research*, 103, 102–107.

Cohen, Gillian, and Rosalind Java. (1995). "Memory for Medical History: Accuracy of Recall." *Applied Cognitive Psychology* 9 (4): 273–88.

Crijns, H., Claeys, A., Cauberghe, V., & Hudders, L. (2017). Who says what during crises? A study about the interplay between gender similarity with the spokesperson and crisis response strategy. *Journal of Business Research*, 79, 143– 151.

Cross, Nigel. (2007). *Designerly Ways of Knowing* (Board of International Research in Design). Birkhauser: Basel.

Davidson J., Sternberg R. (2003). *The Psychology of Problem Solving*. Cambridge University Press.

Dewey, J. (1933). *How we think: A restatement of the relation of reflective thinking to the educative process.* (Boston) DC Health.

Dilla, W., and Stone, D. (1997). "Representations as Decision Aids: The Asymmetric Effects of Words and Numbers on Auditors' Inherent Risk Judgements," *Decision Sciences* (28:3), pp. 709-743.

Driscoll, J., The, B. (2001). The potential of reflective practice to develop individual orthopaedic nurse practitioners and their practice, *Journal of Orthopaedic Nursing*, Volume 5, Issue 2, Pages 95-103.

Fan, Y., Wonneberger, C., Enzi, B., de Greck, M., Ulrich, C., Tempelmann, C., . . . Northoff, G. (2011). The narcissistic self and its psychological and neural correlates: An exploratory fMRI study. *Psychological Medicine*, 41, 1641–1650.

Federal Aviation Administration. (2016). *Volume 3 General Technical Administration, Chapter 32 Manuals, Procedures, and Checklists for 14 CFR Parts* 91K, 121, 125, And 135. Section 12 Safety Assurance System: Aircraft Checklists for 14 CFR Parts 121/135. Retrieved from; http://fsims.faa.gov/PICDetail.aspx?docId=8900.1,Vol.3,Ch32,Sec12.

Gibbs, G. (1988). *Learning by Doing: A Guide to Teaching and Learning Methods*, London, UK: Further Education Unit.

Groen, Y., Wijers, A. A., Tucha, O., & Althaus, M. (2013). Are there sex differences in ERPs related to processing empathy-evoking pictures? *Neuropsychologia*, 51, 142–155.

Hampton, J. R., Harrison, M. J., Mitchell, J. R., Prichard, J. S., & Seymour, C. (1975). Relative contributions of history-taking, physical examination, and laboratory investigation to diagnosis and management of medical outpatients. *British Medical Journal*, 2(5969), 486–489.

Hevner, A. R., March, S. T., Park, J. & Ram, S. (2004). Design Science in Information Systems Research. *MIS Quarterly*, 28, 75-105.

Kassirer JP. (1983). Teaching clinical medicine by iterative hypothesis testing. Let's preach what we practice. *N Engl J Med*.309(15):921-923

Kaufman, J. & Sternberg, R. (2019). *The Cambridge Handbook of Creativity.* Cambridge University Press.

Kilmann, R. H., & Mitroff, I. I. (1979). Problem Defining and the Consulting/Intervention Process. *California Management Review*, 21(3), 26–33.

Korthagen, F. (2001). *A Reflection on reflection*. In Korthagen, F. Linking Practice and Theory: The Pedagogy of realistic teacher education. (New Jersey) Lawrence Erlbaum Associates.

Kuechler, W., & Vaishnavi, V. (2006). So, Talk to Me: The Effect of Explicit Goals on the Comprehension of Business Process Narratives. *MIS Quarterly*, 30(4), 961-979.

Lazare A., Putnam S.M., Lipkin M. (1995). *Three Functions of the Medical Interview*. In: Lipkin M., Putnam S.M., Lazare A., Carroll J.G., Frankel R.M. (eds) The Medical Interview. Frontiers of Primary Care. Springer, New York, NY

Lesgold, A. M. (1988). *Problem solving*. In R. J. Sternberg & E. E. Smith (Eds.), The psychology of human thought (pp. 188-213). New York: Cambridge University Press.

Lyles, M., Mitroff, I. (1980). Organizational Problem Formulation: An Empirical Study. *Administrative Science Quarterly*, Vol. 25, No. 1, pp. 102-119.

Maclean, P. (2005). *A problem well stated is a problem half solved*. From Family Assessment: Integrating Multiple Clinical Perspectives. (Ch 4.), Hogrefe & Huber

Maclean, S. (2012). Critically reflexive practice in social work, NOPT Conference Workshop. Retrieved from: https://www.google.ie/url?sa=t&rct=j&q=&esrc=s&source=web&cd=12&ved=2ahUKEwiW6In4i9LiAhUmURUIHZv6C0cQFjALegQIBRAC&url=http%3A%2F%2Fwww.nopt.org%2Fadmin%2Fwp-content%2Fuploads%2F2013%2F01%2FSIOBHAN-MACLEAN-WORKSHOP-CRITICALLY-REFLECTIVE-PRACTICE-1.ppt&usg=AOvVaw1Iwy1sKLSzmKsZVlLPs8MG

Martin L., Dimatteo M., *The Oxford Handbook of Health Communication, Behaviour Change, and Treatment Adherence* -. Ch 2., p11. Oxford University Press (2014).

Markus, M.L., Majchrzak, A., & Gasser, L. (2002). A design theory for systems that support emergent knowledge processes. *MIS Quarterly*, 26(3), 179–212.

McPherson, M. L., Smith, S. W., Powers, A., & Zuckerman, I. H. (2008). Association between diabetes patients' knowledge about medications and their blood glucose control. *Research in Social and Administrative Pharmacy*, 4, 37–45.

Mintzberg, Henry; Raisinghani, Duru; and Theoret, Andre. (1976). The structure of ' 'un-structured" decision processes. *Administrative Science Quarterly*, 21, 246-275.

Mitroff, I. I. and Featheringham, T. R. (1974). On systemic problem solving and the error of the third kind. *Syst. Res*., 19: 383-393.

Mitroff, I., Emshoff, J., Kilmann, R., (1979). Assumptional analysis: a methodology for strategic problem solving. *Management Science*, 25, 6, 538-593.

Mullarkey M., Hevner, A. (2018). An elaborated action design research process model, *European Journal of Information Systems*, 28:1, 6-20.

Mumford, Enid, (1998). "Problems, Knowledge, Solutions: Solving Complex Problems", *ICIS 1998 Proceedings*. 62.

Orlikowski, W. J. and Iacono, C. S. (2001). "Research Commentary: Desperately Seeking the "IT" in IT Research—A Call to Theorizing the IT Artefact." *Information Systems Research* 12(2): 121-134.

Peffers K., Rothenberger M., Tuunanen T., Vaezi R. (2012). Design Science Research Evaluation. In: Peffers K., Rothenberger M., Kuechler B. (eds) *Design Science Research in Information Systems. Advances in Theory and Practice. DESRIST 2012*. Lecture Notes in Computer Science, vol 7286. Springer, Berlin, Heidelberg.

Polya, G. (1957). *How to Solve It: A New Aspect of Mathematical Method*. Princeton, NJ: Princeton University Press.

Purao, Sandeep & Henfridsson, Ola & Rossi, Matti & Sein, Maung. (2013). Ensemble Artefacts: From Viewing to Designing in Action Design Research, Systems, Signs & Actions, *An International Journal on Information Technology. Action, Communication and Work practices*. 7. 73-81.

Roy, M., and Lerch, J. (1996) "Overcoming Ineffectual Mental Representations in Base-Rate Problems*," Information Systems Research* (7:2), pp. 233-247.

Sandler G. (1980). The importance of the history in the medical clinic and the cost of unnecessary tests. *Am Heart J*. Dec;100(6 Pt 1):928-31

Sarkar U., Schillinger D., Bibbins-Domingo K., Nápoles A., Karliner L., Pérez-Stable E., (2011). Patient–physicians' information exchange in outpatient cardiac care: Time for a heart to heart? *Patient Education and Counseling*, Volume 85, Issue 2, Pages 173-179.

Savoia A. (2011). Pretotype It, 2nd Ed. Retrieved from; www.pretotyping.org /uploads/1/4/0/9/14099067/pretotype_it_2nd_pretotype_edition-2.pdf

Schon, D. (1983). *The Reflective Practitioner: How Professionals think in action*. (London) Temple Smith.

Schraa J., Dirks J., (1982). Improving patient recall and the comprehension of the treatment regime. *Journal of Asthma*, 19(3), 159162.

Sein, M., Henfridsson, O., Purao, S., Rossi, M., & Lindgren, R. (2011). Action design research. *MIS Quarterly*, 35(1), 37–56.

Sein, M., Rossi, M. (2018). Elaborating ADR while drifting away from its essence: A commentary on Mullarkey and Hevner, *European Journal of Information Systems*, 28:1, 21-25.

Simon, H. A. (1957). *Models of man; social and rational*. Oxford, England: Wiley.

Simon, H, and Hayes, J. (1976) "The Understanding Process: Problem Isomorphs," *Cognitive Psychology* (8), pp. 165-190.

Simon HA (1977). *Models of Discovery and Other Topics in the Methods of Science*, Boston Studies in the Philosophy of Science (D. Reidel, Dordrecht, Netherlands).

Spradlin W. (2012). Are you solving the right problem? *Harvard Bus. Rev*. 90(9):85–93.

Smith, G., (1989). Defining Managerial Problems: A Framework for Prescriptive Theorizing. *Management Science*; 35, 8; Social Science Premium Collection pg. 963.

Southard, E. E. (1918). The empathic index in the diagnosis of mental diseases. The *Journal of Abnormal Psychology*, 13(4), 199-214.

Topal, E. (2019). *Deep Medicine: How Artificial Intelligence Can Make Healthcare Human Again*. Ingram Publisher Services USA.

Twomey, M., Sammon, D., Nagle, T. and O'Raghallaigh, P. (2018) 'A check list designed to improve memory recall amongst CF patients', *ECIS 2018: Twenty-Sixth European Conference on Information Systems*, Portsmouth, UK, 23-26 June.

Vaishnavi, V., and Kuechler, B. (2007). "Design Research in Information Systems," IS World. Retrieved from: http://home.aisnet.org/displaycommon.cfm?an=1&subarticlenbr=279.

Venable, J., Pries-heje, R., Baskerville, R. (2012). A Comprehensive Framework for Evaluation in Design Science Research. *7th International Conference on Design Science Research in Information Systems & Technology (DESRIST 2012)* (Peffers, K., Rothenberger, M. Eds), Springer, Berlin, Germany.

Volkema, R. (1983). Problem Formulation in Planning and Design. *Management Science*, vol. 29, issue 6, 639-652.

Wade, R. &. Yarbrough, D.M. (1996). Portfolios: A tool for reflective thinking in teacher education? *Teaching and Teacher Education*, 12, 63-79.

Watson, C. (1976). *The problems of problem solving*. Business Horizon, 88-94.

Weisberg, R. W., & Alba, J. W. (1981). An examination of the alleged role of “fixation” in the solution of several “insight” problems. *Journal of Experimental Psychology: General*, 110(2), 169-192.

Wieringa, R. (2010). Relevance and Problem Choice in Design Science. *The 5th International Conference on Design Science Research in Information Systems and Technology (DESRIST)*. St. Gallen, Switzerland.

Chapter Three

3. Paper 4: Turning Challenges into Design Principles: A Check List for the chronic Patient or carer

3.1. Abstract

This paper takes a *People, Process, Technology, Data* view of two critical information phases *within* a medical appointment to understand the complexities that exist, and the need for memory recall/information retrieval by patients/carers. Our practice inspired investigation is driven by the following motivation: *how might we augment Cystic Fibrosis (CF) patient/carer memory recall/ information retrieval within the elicitation and elucidation phases of the medical appointment?*

Building on extant literature, the paper presents a representative set of 10 key design principles for the design of a check list for use by patients/carers. These design principles have emerged from an ongoing Action Design Research (ADR) study where the artefact went through an iterative design, build, and evaluate process.

The artefact has a number of design elements of value to practice and IS research, of which the most novel is the unpacking of declarative memory into its components, where the check list design maps to "*aid*" the memory type drawn upon by the patient/carer *within* the medical appointment. The outcome is a check list that enriches patient/carer memory recall/information retrieval, reduces stress, increases patient/carer empowerment, improves data quality and the doctor's ability to make an effective diagnosis. More recently the research has led to the production

of a check list booklet which has been distributed to all CF patients/carers within Ireland by CF Ireland. Distribution by the NHS began in early 2020, beginning with the Royal London Children's Hospital, in London. Furthermore, the check list has gone to seven other countries for review/evaluation by their relevant CF bodies.

These findings are both transportable and adaptable to the medical appointments of other disease states. The check list is a particular contribution to memory recall/information retrieval as a class of problem.

Keywords:

Memory recall, Information retrieval, Medical appointment, Check list, Design principles.

3.2. Introduction

Memory recall/information retrieval is a dominant feature of the medical appointment. The importance of memory recall/information retrieval is indisputable as the accuracy and completeness of data gathering in the history-taking phase of the medical appointment determines diagnostic success (Japp et al., 2018). One of the greatest challenges to memory recall/information retrieval is the substantial stress that accompanies many chronic medical conditions. There is also increasing concern surrounding the ever more complex nature of the medical appointment itself and the impacts of same on a patients/carers ability to remember or retrieve information as required (Martin et al., 2014).

Despite this, research has consistently shown that check lists are a very effective device for averting human errors in difficult, pressurised environments (Borchard et al., 2012). Therefore, it is hardly surprising that the use of check lists within the aviation and aeronautics industry has experienced unprecedented growth over the past 30 years. However, their use in the healthcare industry is comparatively recent. Nonetheless, a proliferation of studies has demonstrated their potency at thwarting memory failures within surgical settings (Stock et al., 2015). For instance, when put into operation correctly, they have had a marked effect on patient safety and also on ameliorating amassed errors that lead to surgical omission (WHO, 2010). Although studies have recognised the benefits of check lists within surgical environs, research has yet to investigate the effect a check list may have as an aid to memory recall/information retrieval *within* the context of the medical appointment. In addition, no research has been found that examined how one may

augment Cystic Fibrosis (CF) patient/carer memory recall/information retrieval *within* the *elicitation* and *elucidation* phases of their particular medical appointment?

In order to progress this research agenda this paper uses a *People, Process, Technology, Data* view proposed by Logan (2017) to understand two critical information phases *within* the complex medical appointment ecosystem. Section 3.3 provides a brief conceptual foundation of the medical appointment through Logan's (2017) *People, Process, Technology, Data* lens. Followed by Section 3.4, which explains the research setting and the design process. Then in Section 3.5 we visit the design principles which emerged from the iterative building of the check list in this study. Next, in Section 3.6, we formalise our learning, moving from situated to a more generalised learning. Finally, Section 3.7 brings the paper to a conclusion and reflects on the significance and validity of the check list and its implications, and the design principles mapped against the *People, Process, Technology, Data* lens.

3.3. Background

The complexity and importance of the medical appointment has been a focus of research for many clinical stakeholders, particularly as it has such an impact on communication, data quality, medical decision making, adherence, patient satisfaction, clinician satisfaction, and clinical outcomes (Lazare, 1995). Below we briefly explore memory recall/information retrieval in two key information stages of the medical appointment through an adapted *People, Process, Technology, Data* view (Figure 3-1).

3.3.1. People

The Doctor

The most commonly documented purpose of the medical appointment is to ascertain the health challenge that a patient exhibits *within* the medical appointment, or to "*make the diagnosis*" (Lazare, 1995). Making a diagnosis is a cumulative decision, cultivated from key data, where doctors are required to validate their diagnostic decisions, by reflecting '*in practice'* making modifications to decisions dynamically, in real time (Schön, 1983; Sibbald et al., 2015).

The consequences of poor memory recall/information retrieval in a medical appointment are profound in terms of the quality of information imparted to a doctor, his/her ability to make effective diagnosis and treatment decisions, all of which have vast impacts on patient outcomes (Cohen et al., 1995) and clinician satisfaction (Schraa et al., 1982).

The Patient/Carer

Over time, patients with multiple chronic diseases can acquire increasingly complicated medication schedules and the amount of information that they are required to remember increases sustainably (Martin et al., 2014). Research shows "*that memory for medical history, like other forms of autobiographical memory, is likely to be flawed, incomplete and erroneous*" (Cohen et al., 1995, p.273).

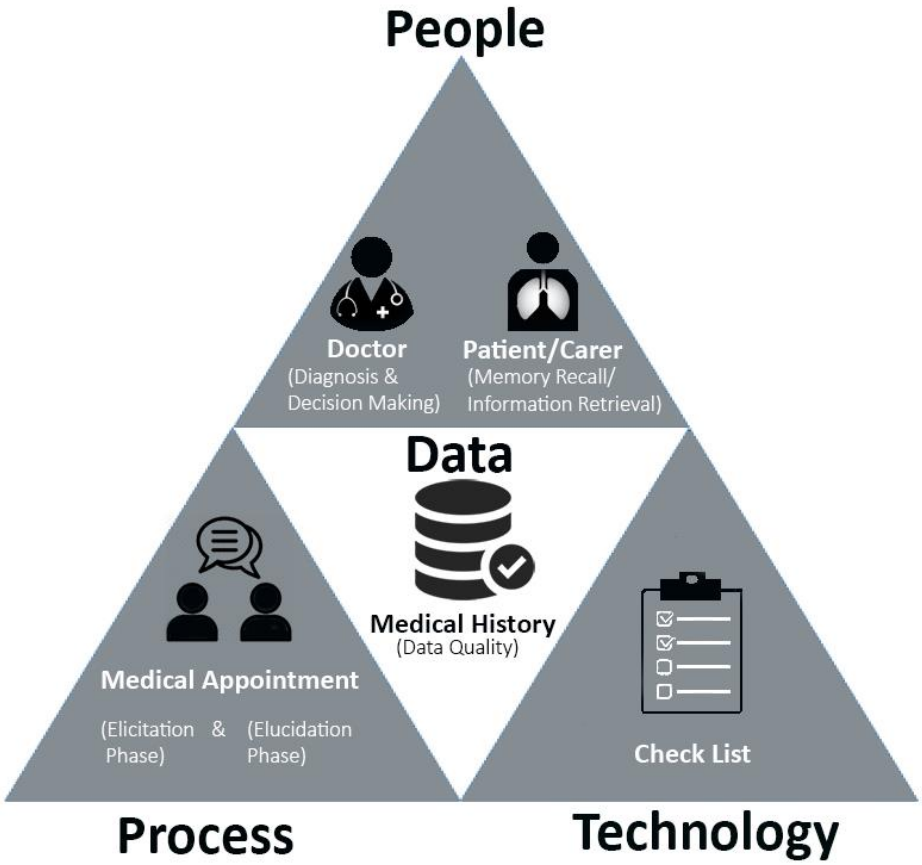


Figure 3-1 People, Process, Technology, Data (inspired by Logan, 2017)

Recollection is also reported to decline as we age (Kessels, 2003), with those in the elderly populace less capable of remembering information effectively (Watson, 2009). In tandem with this, the frequency of medical appointments also poses a major recall challenge for chronic patients/carers, where the details of similar recurrent events can often seem to almost merge into one another (Rubin et al., 2015).

Memory and anxiety levels are also associated with difficulties in information retrieval, with a significantly better ability to remember at a medium level of anxiety, in contrast to low measures or elevated degrees of stress (Kessels, 2003; Jansen, 2008; Safeer, 2005; Ley, 1979). This is often exacerbated by the very

context of the medical appointment itself and of clinical environments in general, which can render effective doctor–patient communication challenging, due to appointments often occurring under severe time constraints and with high degrees of stress (Ong et al., 1995).

Reports maintain that patients fail to remember between 40–80 percent of health-related data imparted to them by doctors almost instantaneously (Kessels, 2003). Research also confirms that as the quantity of material to be remembered grows, the percentage of accurately recalled data deteriorates (McGuire, 1996). At the same time, medical lexicon (which many patients/carers find difficult to understand due to poor health literacy), education level, the form that the information is delivered (oral or written), and patients' beliefs all impact information retrieval (Martin et al., 2014). Consequently, failure to effectively recall health information communicated by clinicians *within* the medical appointments results in diminished health outcomes and reduced patient satisfaction (Schraa et al., 1982).

3.3.2. Process

The Elicitation Phase

In order to reach a correct diagnosis, both doctor and patient/carer participate in the *elicitation* phase of the appointment, which involves a bi-directional conversation regarding the patients' medical history, current wellbeing, current medication and so on (Sarkar et al., 2011). 46% of the time at a doctor's appointment consists of this stage and is required as 99 percent of patient activity happens outside of the hospital or medical appointment (Martin et al., 2014). Clinical studies report that the medical history gathered in this phase of the appointment furnishes the doctor

with 60-80 percent of the data required in order to reach a diagnosis (Hampton et al., 1975; Sandler, 1980; Kassirer, 1983).

The Elucidation Phase

The *elucidation* or the *explanatory* stage of the medical appointment, is the phase in which doctors engage in the communicating of diagnoses, clinical options, self-care plans, in tandem with overall advice regarding the management of a medical condition/s (Martin et al., 2014). Reports show that memory recall/information retrieval of this phase of the medical appointment directly impact patient adherence and other self-managing activities, such as regime change (McPherson et al., 2008).

3.3.3. Data

Medical History

The patient's medical history data is a complicated medical autobiography which represents the accumulation of a patient's health journey, peppered with various periodic medical appointments with their doctor. Essential components of a patient's medical history include symptoms, illness episodes, encounters with other clinicians, medical therapies and medications taken (or indeed not taken) and so on (Cohen et al., 1995). This is the type of data specificity that a doctor requires so they can assemble a complete representation of the patient's health, make an accurate diagnosis and hence to decide on a correct therapy regime (Ibid).

Missing or inaccurate information can have several pernicious effects (Redman, 2016), not only from an economic standpoint; but also, as misdiagnosis and poor decision-making now becomes more conceivable, where patients are often

subjected to unnecessary expensive medical procedures, often causing preventable pain and suffering (Personal Injury Team Ireland, 2017). In tandem with this, a misdiagnosed illness can result in a patient's condition worsening, (leading to life-changing consequences), considerable mental anguish, psychological problems or death (Ibid).

3.3.4. Technology

Check Lists

Check lists have been used in high-risk activities (e.g., nuclear power generation and aviation) as an instrument to support human endeavour (including memory) in critical environments, which are not only complex but also unpredictable (Arriaga et al., 2013). In 2016, the Federal Aviation Administration (p.1) redefined the definition of a check list as "*a formal list used to identify, schedule, compare or verify a group of elements or…used as a visual or oral aid that enables the user to overcome the limitations of human memory*".

Reports indicate that as many as 200,000 to 400,000 patient mortalities occur as a product of medical errors each year (James, 2013), where the absence of effective communication is sighted as the main contributor to these preventable blunders (Solet, 2005). In an effort to ameliorate these defects within the surgical environment Dr Atul Gawande turned to the aviation industry for inspiration. There he discovered the B-17 check list, which became the source of his idea to design a surgical safety check list (WHO, 2010). "*Under conditions of complexity, not only are check lists a help, they are required for success*" (Gawande, 2010, p.45).

The surgical check list has now been put into operation worldwide to cut down on the number of surgical errors and to regulate surgical safety (Ibid). Indeed, when designed and introduced correctly, these check lists have been found to significantly reduce cumulative errors that result in surgical omission, leading to substantial increases in patient safety (WHO, 2010). Moreover, Dr. Gawande projected that between $15 to $25 billion USD per annum would be spared providing the WHO surgical safety check list was introduced into hospitals across the USA (Semel, 2010). The use of check lists in health care is now widespread as they have proven to be so beneficial in preventing memory failures (Stock et al., 2015), more especially when a particular sequence of actions is taken the same way every time (Ibid). However to ensure the maximum value from a check list, choices must be made regarding the maintenance, dissemination and design of these tools (Pronovost, 2014). Indeed the WHO advocates adapting the design of the surgical safety check list to cater for regional needs, a methodology that has shown to be effective in stimulating collaboration and a perception of tenure (Leape, 2014).

Check List Design Concepts

As no memory recall/information retrieval tool could be found for the specific needs of CF patients/carers, the researchers decided to create a check list for use *within* their particular medical appointments. Therefore, as a first step to the design of our artefact, we conducted a review of extant literature in check list design. Well-made check lists codify interventions, eliminate vagueness, and augment consistency (Pronovost, 2014). The check list is determined by its role, nothing is without purpose and in order for it to fulfil its function, its content and design must

fit in with the demands of the environment (Schwesinger, 2010). Table 3-1 portrays a set of three central design concepts, together with five sub-concepts, which not only gives a brief overview or background of check list design, but also constitutes a significant foundation for our design. The value of conducting such groundwork is crucial to selecting the most suitable design approach when conceiving an effective check list. The next section presents the design research methods and the research process for this design study.

Table 3-1 Check List Design Concepts

Concept Type	Concept	References
Function		
Memory Recall	Clear and concise objective/function are paramount to a check list success, as the function of the check list will define its structure and content.	(Simmons & Chew, 2015; Schwesinger, 2010; Gawande, 2010)
	Focus on the key items that are critical and known to be continually forgotten or overlooked.	(Weiser et al., 2010)
Form		
	Form follows Function.	(Lidwell, 2003)
	A Check list should be designed based on the environment that it will operate in, and to the expectations that users will have.	(WHO, 2009)
Colour	Colour should only be used in a purposeful way.	(Schwesinger, 2010)
	Avoid the use of unnecessary colours in check lists	(Gawande, 2010)
	Colours attract human attention.	(Farley et al., 1976; Pan Y., 2012; Eysenck M., 2009)
	If colours are used, make sure that they are in line with those normally used in the proposed setting.	(Hales, 2008)
Structure	Tasks should be presented in list form, logically and functionally, reflect the sequence or flow of activities.	(Verdaasdonk, 2009)

	Table 3-1 continued ….	
	Structuring of data aids human understanding and augments memory recall.	(Ackermann et al., 2016)
	The more structure put on information; the better memory recall will be.	(Mandler, 1967)
	Design a check list as a series of succinct components, made up of a single page where doable.	(Weiser et al., 2010)
	Check lists should have a rigid hierarchy, structured by straight lines, where every unit of data has its own space, with no overlaps, no inconsistencies, nothing but simple two-dimensionality.	(Schwesinger, 2010)
	Apply the Gestalt statutes of design, such as proximity, similarity and unity, making associations obvious, aiding structure.	(Schwesinger, 2010)
	Information is codified, not only in the sequence of characters but also through the relationship of that information to the medium itself where the written content is given a visual framework.	(Schwesinger, 2010)
Categorisation	Explicit categorisation increases memory recall.	(Kessel, 2003)
	Memory recall is improved by *"chunking"*; where low-level sub- fragments of data are joined together into larger high-level significant units.	(Miller, 1956)
	The design must always be consistent, where usability and learnability advance when comparable components have a consistent appearance and function in similar way.	(Nikolov, 2017)
	Components that fit together can be visually categorised by position shape or colour.	(Schwesinger, 2010)
Language	It is critical that the lexicon used in a check list be straightforward, yet preserve the dialect of the area in which the check list is used.	(Weiser et al., 2010)
	Avoid wordiness, but yet be clear and unambiguous.	(Verdaasdonk, 2009)
Usability		
	Complexity results in stress, therefore a check list should be easy to read, understand and to fill out.	(Weiser et al., 2010)
	In tandem with being easy to follow a check list must not take a long time to complete.	(Stock and Sundt, 2015)
	Evaluation of the check list should occur, where feasible, within its designated environment.	(Hales, 2008)

3.4. Design Research Methods and the Research Process

3.4.1. Research setting

Having wrestled with the problem of memory recall/information retrieval (and the stress associated with same) *within* the medical appointment for a couple of years (on a part-time basis), the lead researcher decided to sell his IT business to allow him to research the issue on a fulltime basis, and so it became the impetus of his PhD in 2017.

The primary focus of the research was designing a check list that would not only augment our understanding of the memory recall/information retrieval challenges *within* the medical appointment, but also to evaluate the effectiveness of the tool, in terms of improving memory recall/information retrieval, reducing stress and increasing empowerment. Due to the lead researchers' close ties within the CF community, he quickly gathered support and long-term commitment from Cystic Fibrosis Ireland and recruited CF patients and carers who also wished to address the problem. He also organised a design team with defined roles and responsibilities, which consisted of himself, a CF respiratory clinician and two carers of CF children. This design team had over 100 years of combined CF experience with differing perspectives, that of carer, patient, and clinician.

At its simplest, our research strategy was as follows; to obtain empirical insights by way of rigorous evaluation (of the designed artefact) in the real-world setting of the medical appointment, attended by actual CF patients/carers. Therefore, a further 18 CF patients and carers were recruited (committing to the project), where the final

evaluation team (with their defined role) was made up of seven CF patients (adults) and eleven carers of CF children. Additionally, we sought expert opinion (and project assurances) from CF clinicians, based on their perception of the check list - following its use *within* the medical appointment by their CF patients/carers. Furthermore, our aim was to draw out the key design principles for a check list to aid memory recall/information retrieval *within* the medical appointment, that would contribute to a body of knowledge that others may find useful in tackling similar problems/challenges *within* this and similar complex environments.

3.4.2. Design Research Methods

The methodological approach used in this study is Action Design Research (ADR), originally portrayed as "*a research method for generating prescriptive design knowledge through building and evaluating ensemble IT artefacts in an organizational setting"* (Sein et al., 2011, p.4). Regarded by those in Design Science Research (DSR), as a subtype of Design Science Research (DSR) (Gregor & Hevner, 2013; Iivari, 2015), ADR necessitates knowledge outputs in the form of purposeful solutions for particular real-world problems, directed at a class of problems, via instantiated artefacts (Rogerson & Scott, 2014; Keijzer-Broers & de Reuver, 2016) or design knowledge that has been gathered (Mustafa & Sjöström, 2013; Haj-Bolouri et al., 2016).

As a method involving both practitioner and researcher, ADR centres on designing, building, intervening, and evaluating artefacts in iterative cycles of inquiry, action, and design-oriented behaviours. And while ADR features the key tenets of DSR, for example linking the practical with methodical rigor (Hevner et al., 2004;

Hevner, 2007), it expands beyond DSR by facilitating the "*guided emergence*" (Sein et al., 2011) of artefacts positioned in an organisational environment of interest (Dennis, 2001). This term "*guided emergence*" seeks to invoke the sense of crafting or shaping of both artefact and environment (in which it is placed), as the two entities come to adjust and live together.

This study adheres to the four key stages of the Sein et al. (2011) ADR approach (Figure 3-2): (1) problem formulation; (2) building, implementation and evaluation; (3) reflection and learning; and (4) formalisation of learning. We will now describe our research design process through each stage of this model.

3.4.3. Design Research Process

Problem Formulation

Our practice inspired investigation was driven by the following motivation: *how might we augment CF patient/carer memory recall/information retrieval within the elicitation and elucidation phases of the medical appointment?* Taken together, these two phases should be reciprocal and mutually enforcing, with a shared interchange between the doctor and patient/carer as the outcome (Martin et al., 2014). Hence there was a need for a suitable instrument to aid memory recall/information retrieval *within* these two key phases of the medical appointment, however this must/could not detract from the dialogue between doctor and patient/carer. This artefact, a check list, would encompass the general design concepts and practical recommendations from extant literature for implementing same, but *within* a medical appointment context.

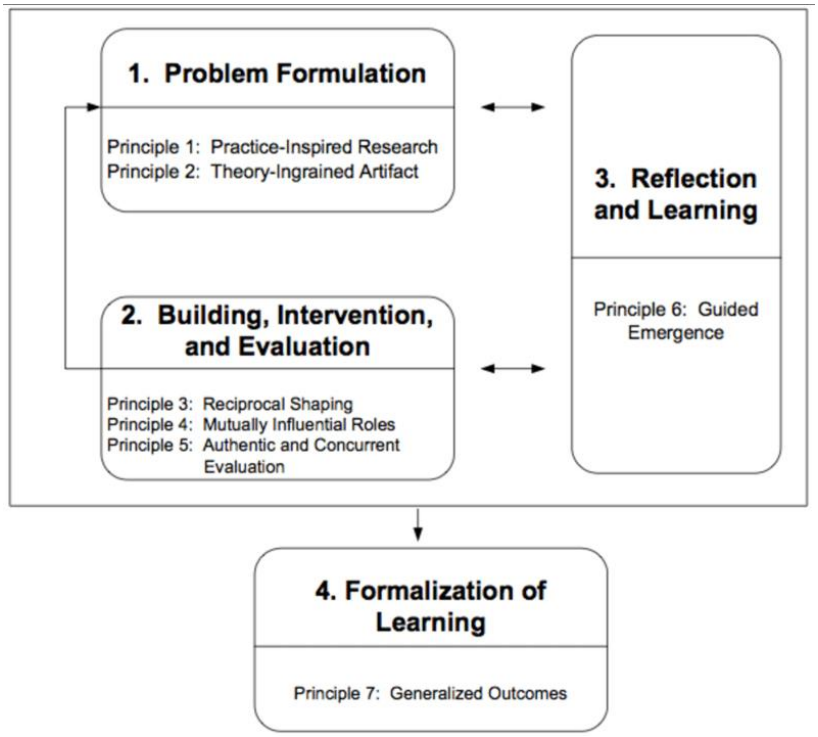


Figure 3-2 ADR method: Stages and Principles (Sein et al., 2011)

Research from diverse disciplines have informed this study and the artefact that has emerged. Our check list is significant as an innovative artefact because no such tool exists thus far *within* the context of the CF medical appointment or other medical appointments as far as we are aware. Abiding by the lexicon of ADR, we define memory recall/information retrieval *within* the *elicitation* and *elucidation* phases of the medical appointment as a class of problem, and our check list (including its design principles), are a contribution to this class. In tandem with this the vast wealth of practical experience from CF patients, carers and doctors has also been hugely significant in the success of this ADR study.

Building, Intervention and Evaluation

We designed an explicit artefact in the form of a check list (knowledge-creation target) and a collection of design principles as a remedy to memory recall/information retrieval *within* the medical appointment. Using ADR as our

chosen methodology for the iterative building, intervention and evaluation, we applied check list design knowledge (from extant literature), leading to the evolution of our emergent artefact shaped by its use in the real-world setting of the medical appointment over time. Our research highlights the design principles that made the design of the check list a success and that, therefore, could underpin the design of other check lists in similar contexts.

The research activity, part of an ongoing ADR project, took place over a 10-month period (2016/2017), in iterative (organisation-dominant) cycles that repeated building, intervention and evaluation as a set of ADR actions. Each iteration included rigorous evaluation by CF patients/carers following the use of the check list *within* the real-world context of their medical appointments. This was followed by learnings, reflections, and often further consultation with literature, after which, agreement was required regarding design improvements to be implemented in subsequent iterations (including the actual intervention step and the planning of same).

In the next section, we reveal how the evaluation process was executed, the qualitative information this exploration is based on, and the qualitative metrics used in the study.

Evaluation process

ADR evaluation is iterative, where each iteration ends with an appraisal of the artefact and "[*c]hallenges organizational participants' existing ideas and assumptions about the artefact's specific use context in order to create and improve the design*" (Sein et al., 2011). Artefacts are evaluated within the context, as

inadequate comprehension of an environment can result in incongruously designed artefacts or artefacts that have undesirable side-effects (March & Smith, 1995).

Wieringa (2010) submitted that "[*t]he only way to produce conditions of practice is to move to practice",* and so, our study entails naturalistic evaluation, involving subjective ex-post conversations regarding the use of an instantiation of the artefact (our check list) by these real users (CF patients/carers), within their natural environments (the medical appointment in this case) in order to solve a real problem. We explain our concurrent evaluation activities through an interpretive lens, directing our focus on interview narratives using four qualitative metrics (as advised by Simmons & Chew, 2015), evaluating *completeness*, *usability*, *robustness* and *impact* (Appendix D), that shaped our sense-making activities (Klein & Myers, 1999) and the assessment of additional cycles where required. The interview participants involved the lead researcher and (1) fellow CF patients, (2) carers of CF children and (3) respiratory clinicians. The ensuing sections provide additional information for each interview type that contributed to our sense-making activities (Figure 3-3).

Interviews with fellow CF patients (DS2 & DS3 – as per Table 1-11): The check list evolved over four iterations, where each of the four versions of the check list was evaluated in real life routine doctors' appointments by each of the CF patients from our group of evaluators. Following which, each patient was interviewed using tele-conference technology to avoid any cross-infection between the CF researcher and CF patient (evaluator). While this initially posed an interesting challenge, it did not hinder the evaluation (as first thought), as both participants in the interview

were determined to maximise the value that the dialogue would bring to the artefacts design, and more importantly to bring to fruition the value that such a tool would bring to their respective medical appointments. Despite the (precautionary) interview workaround, it was felt that the patient/researcher, patient/evaluator dynamic worked extremely well in terms of the beneficial feedback/insights gained from the discussions vis-à-vis their experiences of using the check list *within* the medical appointment, their thoughts, and any ideas they had for design improvements which were subsequently fed into the design of the check list. Indeed, the quality and openness of these interviews (owing to the patient-to-patient dynamic) facilitated our quest to take the check list design past perceived boundaries, to foster a more holistic design, one that encapsulated the real needs of patients' living with a chronic condition and the challenges of memory recall/information retrieval *within* their medical appointments.

Interviews with CF carers (DS2 & DS3 – as per Table 1-11): Our CF carers met the lead researcher in face-to-face interviews as cross-infection was not an issue in this situation. The benefit of the CF carers perspective to the study was very different in terms of the user dynamic they offered, illustrating the stark reality of the difference between being a user having a critical condition and a user looking after a child with a serious illness. Therefore, a central aim for the evaluations with CF carers was to establish whether the designed instantiation gave them the confidence and appetite to continue using the check list. The feedback in these interviews, where CF carers discussed and reflected on their experiences of using the check list at their children's medical appointments, was then inputted into the design of the artefact.

Feedback from clinicians (DS4 – as per Table 1-11): In addition to the above dialogues, we also spoke with CF clinician's in the local hospital in early 2017 to establish their opinion on what we were trying to do and what we had done. We sought to obtain a 360-degree stakeholder perspective, to avoid any oversights and to grasp any astute nuggets of advice regarding our check list design. For example, we hoped to address the concerns that some doctors may have had, and to comprehend why some doctors did not embrace what we were trying to achieve. Studies have shown that even in successful implementations, some doctors can resist partaking in check list initiatives', mainly due to the perception that it takes up too much of their time (Leape, 2014). However, we were acutely aware that the impact of patient/carers interventions often hinges on the mindsets and behaviours of other stakeholders within the medical ecosystem (Rosen et al., 2014). Moreover, we needed to know if they felt that the check list had aided the *elicitation* and *elucidation* phases of the medical appointment, in terms of: (1) the quality of information that was now being imparted by their patients/carers and (2) the quantity of *explanatory* data now retained by the patient/carer. In some cases, we merely presented the check list to a doctor for their expert opinion, whereby they would engage in a type of cognitive walkthrough (using the artefact mentally and 'walk' through a specific task, for example the *elicitation* phase of the medical appointment, spotting any latent problems that could ensue) (Mazza and Berre, 2007).

Reflection and Learning

Akin to Hustad & Olsen (2014) and O' Raghallaigh (2011) we describe our reflection and learning in terms of a process of sense-making. Fundamentally it can be seen as *"... a way station on the road to a consensually constructed, coordinated system of action"* (Taylor and Van Every, 2000, p.275), whereby participants try to decipher and reflect on happenings in order to make individual and a shared sense of it (O'Raghallaigh, 2011) and to subsequently "*... enact this sense back into the world to make that world more orderly"* (Weick et al., 2005 p.410). That is to say sense-making "…*is a kind of creative authoring on the part of individuals and groups who construct meaning from initially puzzling and sometimes troubling data"* (Brown et al., 2008, p.1038). Figure 3-3 summarises the actions that embody our sense-making approach and depict how: (1) we engaged the ADR method, (2) the actors involved (patients, carers and doctors), (3) the elements informing the emerging artefact (literature, CF patients/carers wisdom and the professional knowledge of clinicians), (4) the practice of utilising principles of the hermeneutic circle and finally (5) the formalisation of learning.

As our evaluation activities were conducted through an interpretive lens, it was therefore logical to use hermeneutics, the study of interpretation, or specifically the process of coming to understand a text (Lee, 1994; O'Raghallaigh, 2011). Here text (from an interview for example) is something that must be decoded and so, can comprise of formalised beliefs, conveyed thoughts (either verbal and nonverbal in nature), and actions – all of which can articulate a particular connotation within a particular setting (Ricoeur, 1984; O'Raghallaigh, 2011). The idea of a

hermeneutical circle is used to convey a systems-oriented concept whereby a change in the interpretation of one passage (of text) has the effect of moving through and changing the understandings of other extracts and the manuscript as a whole (Lee, 1991).

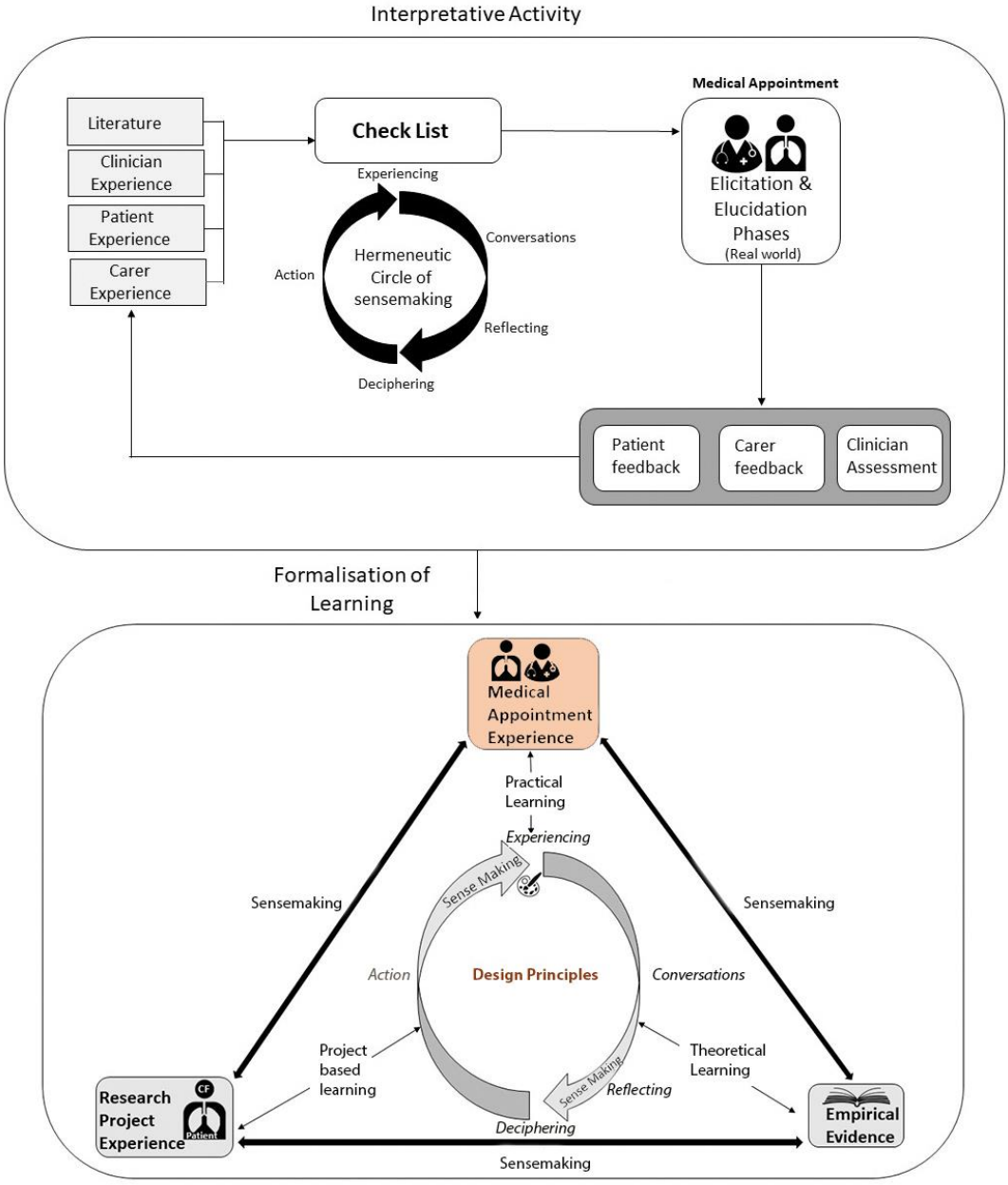


Figure 3-3 The iterative practice of 'build, intervention and evaluate' as an interpretative activity and the Formalisation of Learning (inspired by Hustad & Olsen, 2014)

Consequently, the idea of a '*circle*' is to depict this continuous movement to and fro between a section of text and the complete document, where each iteration around the circle "… *brings the meanings of the different parts into greater consistency, or closer harmony, with one another, as well as with the whole*" (ibid p.349). Therefore, the result of an evaluation can be reflected upon in terms of a hermeneutic circle that stems from the value of an artefact as understood (and articulated) by a stakeholder and the ensuing endeavours of other stakeholders to collectively validate the interpretation so that a shared understanding is attained regarding the true value of the artefact and agreed goals. Of note when evaluating an artefact, it must be appreciated that the interpretations of stakeholders will be influenced not just by the artefact itself but also by the perspective and experiences of each stakeholder.

We sought to ensure that the knowledge claims emerging from our design research initiative were appropriately grounded via theory, practice and project-based learning. Therefore, prior to taking action, we established as wide a frame of reference as possible, by fusing material from our interviews with our findings from literature and the consultations with our clinicians. By then combining these elements, we achieved a more effective check list design in line with our stated research aim.

Hence, topics/insights emerged (DS 5 – as per Table 1-11) through the interplay amongst stakeholders, consisting of CF patients, carers, and doctors. It was thought logical and strategic to have a patient, two carers and a clinician in the design team and in the process of sense-making, because it facilitated the opportunity to examine

each other's beliefs and viewpoints. That is not to say that these conversations always went smoothly, on the contrary they sometimes became slightly heated due to the emotive nature of the problem, together with the complexities of the medical appointment environment. Equally, it was felt that this emotion or passion, was often the driving force behind the enriched conversations and insights that often emanated out of these sessions. This study is based on findings/insights from literature, interviews, together with the documentation and narratives from our design workshops, all of which were combined, integrated and scrutinised according to the guidelines proposed by Kvale et al., (2009).

Formalisation of Learning

While sense-making is predominantly concerned with arriving at a consensual understanding, sense-giving (seen by many as the logical extension of sense-making) is primarily concerned with shaping this understanding and disseminating the output of this understanding to others (Gioia & Chittipeddi, 1991). So, when formalising the learnings of evaluation (Figure 3-3), it is not just a process of sense-making and the reporting of same that is of importance, but also of sense-giving in disseminating an understanding of the value of the artefact to others. Consequently, this ongoing iterative process facilitated an initial understanding of the individual elements to be considered, through to an emerging comprehension of the interrelationship of these components as a whole, to an overall interpretation of the final artefact developed in the context of the medical appointment. This final output of a concluded conundrum embodies the generalised outcomes and knowledge

contribution of this ADR study. The next section depicts the design principles that evolved as part of the iterative development of the check list.

3.5. The Iterative Emergence of Design Principles

This section of our paper imparts the iterative design of a check list and an emerging set of design principles (DP). Note a representative data set behind each DP can be seen in Appendix R. By enriching the experiences of check list use by CF patients/carers with the knowledge obtained from extant literature, we progressively applied and/or extended various design principles to stimulate memory recall/information retrieval amongst this cohort of patients /carers. The part of the paper also states some of the main challenges we faced in this process.

McAdams (2003, p.357) states that a design principle is "*a recommendation or suggestion for a course of action to help solve a design issue*". In the context of this study, we visit our design principles (artefact based) as they arose in Table 3-2, either as a chief topic of conversation/focus, or reflection after an iteration. Some design principles appear in more than one iteration, to reflect the additional contribution they have made within that iteration, albeit to a lesser level than the iteration in which they are primarily discussed.

Table 3-2 DPs within each iteration

Iteration / Design Concept	V1 (Sept. 2016 - Nov. 2016)	V2 (Nov. 2016 - March 2017)	V3 (Feb 2017 - April 2017)	Booklet (Jan 2019)
Function	**DP1**		**DP10**	
Information Retrieval/Memory Recall	**DP2**	**DP7**	**DP8**	**DP9**
Form	**DP5**			**DP9**
Colour		**DP7**		
Structure	**DP4**			
Categorisation	**DP3**			
Language	**DP6**			
Usability	**DP5**	**DP7**		

3.5.1. Iteration 1 (September 2016 - November 2016)

3.5.1.1. The Challenge of Function

Design Issue

All too often designers can become fixated on a solution rather that first trying to understand the problem, described by Nigel Cross as "*solution fixation*" where designers "*may be too ready to re-use features of known existing designs, rather than to explore the problem and generate new design features."* (Cross, 2006, p.104). In the 1st century B.C., Vitruvius, the famous Roman architect and engineer declared that "*utilitas"* or function was the first requirement of a good design (Vitruvius, 1960), after which one moves to form, or put another way, form follows function (Lidwell, 2003). Therefore, the first question we needed to answer was *what function will our check list have within the medical appointment of CF patients?*

Course of Action

With this in mind, we held our first design workshop in September 2016, where our Design and Build team sought to understand the complexities of the problem we were trying to solve. In tandem with the expertise in the room, which encompassed perspectives from a CF carer, CF patient and CF clinician (comprising of over 100 years of combined CF experience - as previously stated), we also consulted the literature and used a number of Design Thinking tools such as journey mapping, role playing and empathy maps to capture as much information as possible about the real complexities *within* the medical appointment process, including stress and empowerment and the problem of memory recall/information retrieval.

We finally arrived at our check list function; it was going to aid our understanding of the information needs (later becoming memory recall/information retrieval) of CF patients/carers in routine doctors' appointments and the impacts of the artefact on poor memory recall, stress and empowerment *within* the medical appointment (Twomey et al., 2018).

Design Principle

Therefore, the first design principle to emerge states:

DP 1. *In order to ensure the successful design of a check list for use by patients/carers within the medical appointment, one must have a clear understanding of the check lists' function within the appointment.*

3.5.1.2. The Challenge Categorisation

Design Issue

As referenced earlier, as the quantity of information to be remembered grows, the percentage of material that is retrieved accurately deteriorates (McGuire, 1996). In tandem with this, information categorisation also affects recollection (Kessels, 2003; Safeer, 2005). The first challenge we encountered was twofold, how might we decide on the essential data elements and how should we categorise them within the check list?

Course of Action

Successful implementation requires adapting a check list to local routines and expectations (WHO, 2010), without overlooking key context and connotation (Schraa et al., 1982). Therefore, at our first workshop we gathered what was deemed to be the most important or critical information that the check list needed to capture for the medical appointment. This posed a major challenge in itself, as now the amount of "*post-it*" notes (each with a data element deemed to be important) that the design team had accumulated on the wall, far extended anything that could be put onto two sides of a piece of paper. Moreover, to improve understanding and recall, one needs to be explicit, prioritise and encapsulate the major data points (Jansen, 2008).

After much debating, coupled with medical appointment role playing (including the analysis of the subsequent narratives) we settled on what we agreed were the "*killer items*" that patients or carers not only struggled to remember, but had to

recall/capture *during* the *elicitation* and *elucidation* phases of their appointments. And so, having pulled together the essential items of CF related information, we now faced the arduous task of categorising the information. We first began categorising according to human biological systems i.e., respiratory, renal etc, but this form of grouping while making sense to the clinician, did not work for the CF patient/carers, as it was deemed unexpected and did not combine into larger high-level meaningful entities (Miller, 1956). We needed to find a suitable way to cluster the data elements so that patients/carers would not only instantly recognise them, but that they would also clearly communicate a design's function and intent. The answer lay in the medical discourse of the appointment itself. For example, in Table 3-3 the doctor starts the conversation by asking how the patient is and whether or not he has any symptoms and finishes by asking whether the patient has any questions.

Table 3-3 Discourse at the start and end of medical appointment

Actor	Comment
	Start
Doctor	"Hi Michael, how are you? How have you been getting on since I last saw you?"
Patient	"Not too bad, I had an infection, which has more or less cleared up with the antibiotic I took, but I still have a little bit of postnasal discharge which doesn't seem to be clearing up, which is quite annoying, normally it would be gone by now."
Doctor	"Ok, anything else to report? Any other changes, bouts or symptoms?"
Patient	"No….. not really, nothing really comes to mind."

Table 3-3 continued …

	End
Doctor	"Do you have any questions?"
Patient	"Yes actually, when do I go and get my flu vaccine?"
Doctor	"I'd say get it in October, Michael please. Anything else?"
Patient	"No that's perfect thanks, see you next time."

Hence, we categorised according to narrative patterns *within* the medical appointment. The only deviation we had using this approach was in the key metrics section of the check list, as this may be populated throughout the course of the appointment and therefore does not follow a particular dialogue flow. Nevertheless, keeping all essential results together within the one category made logical sense to both CF patients/carers. We knew we were making progress, when one of the CF patients who had used the check list in a real-life medical appointment said "*you know, I have to say, this simple thing actually works and really makes sense"*.

Design Principle

Two design principles emerge from the categorisation challenges that were encountered and state:

DP 2. *It is essential to focus on the vital details that the patient/carer struggle to remember but are also essential to recall/capture within the medical appointment.*

DP 3. *Categorise data elements according to emergent sections, arising from the analysis of narrative patterns within the medical appointment, with elements grouped as expected and understood by the patient/carer.*

3.5.1.3. The Challenge of Structure

Design Issue

Psychological theory and associated empirical literature propose that the structuring of information not only augments human comprehension, but additionally it serves as an effective memory recall/information retrieval instrument (Ackermann et al., 2016). Therefore, the third challenge faced by the design team was how to best structure the categorised words and graphical elements, adapting the check list to CF medical appointment.

Course of Action

The importance of this aspect of design rests in human cognition, where human-beings continually search for data patterns, in their efforts to comprehend, where the more structure they can put on information received through their senses, the better their recall will be (Mandler, 1967). Producing such graphical externalisations really challenged us with our less than adequate comprehension of the design domain since, unlike language, *"... graphics force a determinate representation that is severely limited in terms of the amount of abstraction that can be expressed"* (Cox and Brna, 1994, p.7). How would we arrange the content for the check list, ensuring a rigid hierarchy, where each element of information has its own space, with no overlaps? What visual elements should we see first? These

questions are important as human perception is built in part on organising the information we receive from our senses, with accumulated schema and patterns in our minds, where we understand phenomena more swiftly if they align with our expectations and beliefs, and if items are familiar and repeated (Schwesinger, 2010).

The structuring of the check list took place over several design workshops, where initially as expected there was visible frustration amongst some participants, who endeavoured to foist some subjective structure on all the data we had amassed. This is exemplified by, "*how the hell are we going to arrange this, so that it makes sense and we don't all go mad from it?"* It even got to a stage where one carer on the design team said, "*are we wasting our time here, is it just too damn complex?*" Thankfully however, the clinician in our design team came up with the idea of structuring the check list according to the clinical workflow of the medical appointment (Twomey et al., 2018), i.e., the step-by-step data assembly/direction procedure that a clinician engages in at a medical appointment as defined by Sarkar et al. (2011), so that the patient or carer would not have to adapt themselves to any peculiar demands of the check list.

The artefact that we ventured to create had to "*tick the box*" in a number of key areas: satisfy the information capture requirements of the CF patient/carer, and structured in a way that afforded it to the flow of the medical appointment, the idiosyncratic interpretations that CF patients/cares would place on the structure and the environment itself. After several role plays and scrutiny of the medical appointment workflow, we eventually arrived at a structure that started to make sense, the check list structure now aligned to the workflow, and critically to the

expectations of the CF patient/carer *within* the medical appointment. Visual elements including specific sections/categories were now placed adjacent to each other, creating visual "*blocks*" to convey the information as being connected, guiding the eye through the content, for example "*current symptoms*" was placed at the start of the check list. The benefit of proper structure is supported by the following statement made by an adult CF patient "*As a result of coming so prepared, with everything so well laid out in the check list, I really felt I could cope a lot better and that it was easier to remember stuff"*.

Design Principle

The fourth design principle emerges from the structural challenge that we encountered and states:

DP 4. *Structure the check list according to the workflow of a medical appointment, with elements sequentially aligned as required, understood and anticipated by the patient/carer.*

3.5.1.4. The Challenge of Usability and Form

Design Issue

Like other innovations check lists have to tackle both technical factors (the details of medical environment for example) and adaptive issues, which often go beyond the straightforward embrace of practices and try to cope with more extensive issues, such as context sociological issues and human psychology (Henig, 2016). For instance, recall is also affected by the form that the information is delivered (oral or written), and patients' expectations (Martin et al., 2014).

Therefore, the challenge we faced was how to make the check list as simple as possible to use, whilst still functional in terms of aiding memory recall/information retrieval *within* the medical appointment, without the designed artefact interfering in the important dialogue between CF patient/carer and the doctor.

Course of Action

We made sure that the check list was simple to follow, and relatively quick to complete (Stock et al., 2015). We sought to train the patient/carer to become experts in notetaking/brevity, whilst avoiding the omission of essential medical information. Through the correct use of structure, categorisation, and the simplest of instructions in each section (to guide what needs to be completed *before* and *during* the medical appointment) the artefact became "*self-revealing*", so that it was obvious to patients/carers what needed to be done and how it should be done.

Research confirms that humans, as part of information sense-making, engage in a codification process, which not only involves the sequence of characters, but also occurs through the relationship of that information to the medium itself (Schwesinger, 2010). The question we now faced was whether or not the check list should be an app of some kind, or paper based? As a very simple experiment, we created an excel spreadsheet version of the check list and tested interacting with the spreadsheet (on a smartphone), whilst engaging in simulated appointment conversation with the clinician in the design team. It became clear that using the check list on the smartphone was hindering and frustrating the dialogue between the carer and the doctor to an excessive degree. Exemplified by a comment from the clinician "*folks this isn't working for me, I can't hold a conversation with a*

patient like this, waiting for them to get their heads out of their phone. I have other patients to see. This is taking far too long".

On the other hand, when we conducted the same test using a paper-based version, the discourse was relatively unencumbered. While some may argue that this experiment is too rudimentary, we decided to initially proceed with a paper-based check list. It must be appreciated that at the time we were unsure how patients/carers would even take to the check list; would they even use it? However, in our evaluation of version 2, comments made by one of the mothers were quite encouraging "*My son who is 13 years old can fill it out"*. However, we were equally reminded of the real limitations of paper and the current expectations that people have, "*My 13-year son was surprised that the interface was not digital, an app would be able to tell me more over time, the sheet can't do this".* Interestingly, another patient gave a different perspective "*I used to take notes on the phone, but this is so much better".*

Moreover, many tools can force diverse levels of constraint on design. Instruments (like a pencil and paper) are more amorphous and only enforce moderate limitations on the designer, and they thereby present an augmented sense of liberty to the designer to embrace his/her creativity as ideas come to mind. As the check list in this study was paper based, it remained very straightforward to modify. The delivery of static solutions, in which fundamental functionality is locked down, will not endure in complex real-world settings (Arias et al., 2000), such as the medical appointment. Therefore, it is critical to preserve the efficacy of tools in the face of constant change (Ibid). However, as a cautionary note, we would advocate testing

the technologies available when designing a new check list, as with the pace of advancements in technology our findings (in DP 5) will, we expect, change with time.

Design Principle

The fifth design principle emerges from the usability challenge encountered and states:

DP 5. *A check list should be paper - based, in order to avoid interfering with the critical medical discourse between the patient/carer and the doctor within a medical appointment.*

3.5.1.5. The Challenge of Language

Design Issue

Health literacy is defined as "*the degree to which individuals have the capacity to obtain, process, and understand basic health information needed to make appropriate health decisions"* (US Dept. of Health and Human Services, 2019). The most reported predictors of deficiencies in health literacy are age, education, ethnicity, and income level (Paasche-Orlow et al., 2005). When a doctor and patient/carer participate in dialogue, it demands complex cognitive processing capabilities (Morrow et al., 1992), where a patient's/carer's health literacy is fundamental to the comprehension of imparted health information, and is also vital in their ability to remember medical information (Ley, 1988). Health literacy proficiencies are not static, and often depend on the status of a patient's medical condition or stress levels (Martin et al., 2014). Not surprisingly, individuals with

poor health literacy are reported to have inferior health status and clinical outcomes compared to those with adequate health literacy (Martin et al., 2014).

Therefore, the challenge we faced was how to make the language in the check list as simple as possible, whilst still functional in terms of compression and aiding memory recall/information retrieval *within* the medical appointment.

Course of Action

Successful health literacy strategies are those designed to augment comprehension *within* the *elicitation* and/or the *elucidation* phases of the medical appointment (Martin et al., 2014), where interactions are reported to be more fruitful when doctors and patients/carers draw from a shared lexicon (Doak et al., 1996; 1998). Taking this into consideration it was critical that we used language appropriate to those participants with a lower educational background. Hence, we again studied the doctor patient narratives from real medical appointments and, in conjunction with this, we reviewed our interviews to ascertain what the patient's/carer's stories/experiences might reveal regarding language. We discovered that several words hold different connotations in both lay and clinical context for certain patients/carers, for example the word "*negative*" in layman's terms, is often perceived as unhealthy, a finding supported by Schwartzberg et al. (2005). Not surprisingly and previously reported by Doak et al. (1998), we found that words conveying value such as "*excessive*" and "*regular*" were also challenging for patients/carers to comprehend, especially in cases where they were not provided with related contextual information.

Therefore, we decided we would use plain language, also referred to as "*living room language,"* or communication that utilises short, simple, non-medical words that are easily understandable (Davis et al., 2002). And so, we endeavoured to match patients'/carers vocabulary, incorporating consistent succinct sentences containing simple everyday words, and using the active voice as recommended by Doak et al., (1996). As "*cued recall can be used to elicit memories in response to cues*" (Radvansky, 2017. p.85), we also used language that we learned (via a number of focus group workshops) acted as a retrieval cue(s), thereby assisting in the retrieval of information *within* the medical appointment as personified by - "*It triggers questions and other pieces of information, that I can now ask or write down and ask later in the appointment"* - Mother of CF child.

Design Principle

The sixth design principle emerges from the language challenge encountered and states:

DP 6. *Language in a medical appointment check list must be concise, and yet clearly understood by the patient/carer.*

3.5.2. Iteration 2 (November 2016 – February 2017)

3.5.2.1. The Challenge of User's Attention

Design Issue

During the course of an evaluation of our first check list (Appendix D) one of our participants, a CF parent, reported difficulty finding her way back to where she was

within the check list, having been distracted by her child's coughing spasm *during* a particular medical appointment. The design team deliberated on how we might overcome this issue caused by the uniformity of colour throughout the check list. We discussed using colour to differentiate the different sections within the check list. However, there was some debate amongst the design team as to whether colour should be used in the check list design; one member of the design team referenced Daniel Boorman from the Boeing Company who advocated the avoidance of unnecessary colours (Gawande, 2010). Therefore, the challenge we faced was how to assist the user in finding their way back/to specific sections/fields within the check list, *within* the stressful environment of the medical appointment.

Course of Action

We decided to turn to the literature for further guidance, and there we unearthed how colour operates as a potent data conduit within human cognition, taking hold of attention, via visual stimuli, where an entity can seizes our interest (Bundesen et al., 2005; Wolfe, 1994). In conjunction with this, the more thought given to a tangible stimulus the greater the likelihood that an entity will be encoded in long-term memory storage (Sternberg et al., 2009). Colour also has the potential to augment the likelihood that stimuli within a setting will be encoded, stored, and retrieved effectively and therefore could play a significant role in improving memory function (Wichman et al., 2002). Additionally, colour is seen to have a wide-ranging effect on humans (Elliot and Maier, 2014; Pryke et al., 2007), where its effects extend from alterations in emotion (Kaya and Epps, 2004), physiology

(Dreiskaemper et al., 2013), to changes in human behaviour (Cuthill et al., 1997; Pryke, 2009).

Accordingly, we decided to go in opposition to the recommendations against the extensive use of colour in check list design and follow the literature on the use of colour for memory and attention. We began colour coding each category of information within the check list using specific combinations of colour. This took considerable time, where we sought to achieve the most effective blend of colour, producing the greatest degree of distinction. We also had to be cognisant of what colour combinations would enhance readability and user experience, particularly for people with different types of colour blindness. The check list colour palette had to aid the design, ensuring it functioned aesthetically while also meeting the team's objectives in terms of attention, memory, tone and feeling?

For example, we applied bright colours to the '*Questions for the doctor'* and the '*Comments by the doctor'* sections (Appendix L), pulling the patient's attention diminishing the chances of them leaving an appointment without asking important questions or highlighting any concerns that they might have. Mika et al. (2007) contend that the very act of publicising questions empowers patients to ask questions, and also aids them in prioritising the questions of greatest consequence to them. We endeavoured to create a design where patients/carers would eventually remember sections based on their colour, where grey meant "*my key metrics*" or yellow "*that's where I record all my medicines*". We put the new iteration of the check list out amongst our evaluators to see how it worked in practice, *within* the real world setting of the medical appointment.

Interestingly, the use of colour to differentiate the various sections within the check list certainly enhanced the artefacts effectiveness, where patients and carers reported an increased sense of logic. As we had hoped, the majority of patients/carers now reported remembering categories according to their colour, for example they recalled "*key Metrics*" as grey, "*medications*" as yellow and so on. Furthermore, significant improvements were also reported in both memory recall/information retrieval and the ease of finding one's way back to a particular section (described by one patient as "*effortless*"). Moreover, the colours in the check list design were described as "*energetic and not excessively serious*". The young mother (referenced earlier) made the following comment after using the amended check list "*With the check list for the first time I could really hear what the doctor was saying to me*" (Twomey et al., 2018).

Design Principle

The seventh design principle emerges from the challenge of acquiring a user's attention and states:

DP 7. *The correct use of colour is vital within a well-designed check list to facilitate memory recall/information retrieval and to draw the patients'/carers' attention*.

3.5.3. Iteration 3 (February 2017 – April 2017) & Booklet (Jan 2019)

3.5.3.1. The Challenge of Memory Type

Broadly speaking, human memory is the cognitive capacity that allows for the recollection of events that individuals have experienced in the past, and to recall them later on (Danziger, 2008). In cognitive psychology, particularly from an

information-processing standpoint, memory is portrayed by and large as a process in which external data from our senses is encoded, stored, and retrieved (Ibid). In specific social contexts, for example the medical appointment, we have seen how a medical diagnosis frequently hinges on the accuracy or quality of the information that a patient recalls from memory (Cohen et al., 1995).

In human memory, it is common to refer to long-term memory (LTM) as either implicit/nondeclarative memory (which does not require conscious awareness and so refers to memories that are not normally articulated by a person, but that still effect our lives) versus explicit/declarative (memories that are easy for a person to state and speak about, as the person is consciously working on trying to remember something). This is the aspect of LTM that became the focus of our research in the context of the *elicitation* and *elucidation* phases of the medical appointment.

Design Issue

We started our research by trying to make sense of the problem that patients/carers experienced *within* their medical appointments, where a significant amount of time was spent on how we initially defined/comprehended the problem of memory recall/information retrieval. This was critical as the actions we would take, and the claims we would make to justify those acts, were all interwoven. For example, arriving at a shared schema regarding the translation of the doctor patient narrative into memory recall/information retrieval challenges, and then applying same to the check list design was one the first complications that the design team encountered in our sense making activities. Thus, our initial focus was to reduce this sense of ambiguity and to improve our understanding of the problem domain.

Course of Action

This was achieved after much deliberation and exploration of extant literature, where finally we decided to simplify the complexities of memory recall/information retrieval by unpacking declarative memory into its components (Appendix J), we began by studying doctor patient dialogues supplied by consenting patients/carers, assigning declarative memory components to each sentence or group of sentences. We also matched each comment made by the patient/carer to the declarative memory component used, thereby enabling us to comprehend the complexities of conversations *within* the medical appointment, and the demands that it places on the patient/ carer, be it recalling a specific event (episodic memory), a time period/s (autobiographical memory), something that one must remember to do (prospective memory) or a combination of declarative memory types.

Ensuring that the check list design mapped to "*aid*" the memory type drawn on *during* the doctor patient discourse *within* the medical appointment was the next major undertaking. And so, we set about making it possible for the check list to capture "*remember to do*" items (crucial *within* the medical appointment), for example remembering to report symptoms "*current symptoms*" (Figure 3-4), so that we might ameliorate the bane of forgetting to carry out an action *within* the medical appointment. In other words, the check list also acts as a prospective memory (remembering to remember) device *within* the medical appointment.

A single check list as an entity facilitates the capture of a particular appointment, on a specific date, as an event that has occurred, that can be referred back to at a later date, and so aids the episodic memory of the patient/carer regarding that

medical appointment. However, we were also necessitated to aid a patients/carers autobiographical memory, and while theoretically one could file away a single printed check list in a folder *after* each medical appointment, we decided that this would not suffice.

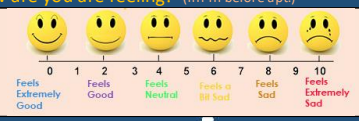
Appointment Check List	
Reason for apt. (Please Circle one - fill in before apt)	
Routine Apt. / Last Problem / Annual Assessment / Other	
Doctor/ Clinician:	**Date:**
Current Symptoms (fill in before apt.)	Date of onset: (fill in before apt.)
1	
2	
3	
4	
How are you are feeling? (fill in before apt.)	What is making you feel this way? (fill in before apt.)
	
Current Medication & doses: (fill in before apt.)	
1	15
2	16
3	17
4	18
5	19
6	20
7	21
8	22
9	Changes to medication: (fill in during apt. if required)
10	1
11	2
12	3
13	4
14	5
Physiotherapy (fill in before apt)	Physio Therapy Changes (if any)
Airway Clearance:	1
Frequency:	2
Exercise /Activity:	3
Key Metrics (fill in during apt)	Nutrition (fill in before & during apt)
Height:	1
Weight:	2
Liver Function:	3
BMI:	4
FEV1:	5
FVC:	Bowels (fill in before apt)
O2 sat:	Abdominal pain:
Auscultation:	Bowel Motions:
Sputum Color/Culture:	Odour:
Blood Sugar:	Colour/Consistency/Form:
Bone Density:	GI Scans:
Urine /Glucose:	Bloods Other (fill in during apt)
Liver Function:	1
X-Ray	2
Blood Pressure:	3

Figure 3-4 Version Three of Check List (Twomey et al., 2018)

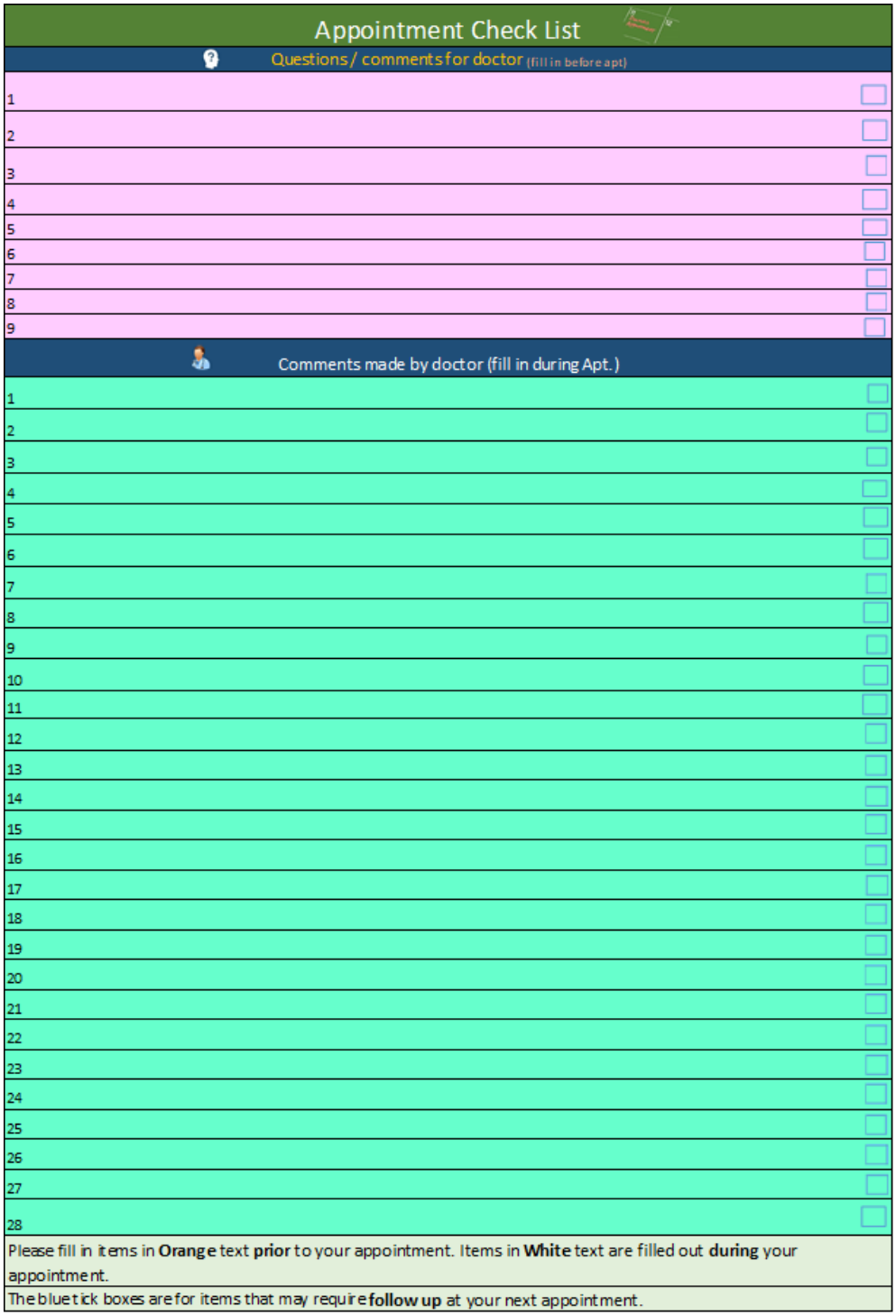


Figure 3-4 Version Three of Check List (Twomey et al., 2018)

And so, in early 2019, after iteration 3, we decided to create a professional, physically robust booklet (Figure 3-5), which also involved the input of a

professional graphic designer to prepare the check list itself for the booklet publication (see Appendix K for the final check list).

Figure 3-5 The Check List Booklet

Contrary to Weiser et al.'s (2010) advice of limiting the check list to one page, we spread the check list spread across two pages of the booklet, allowing the patient/carer to place it physically and firmly on their lap *during* a doctor patient dialogue, removing the need for a table or support. Containing 28 check lists, the booklet liberates the patient/carer from the requirement to print a check list prior to a medical appointment. At once, all check lists are instantly held together in one repository of medical discourse, thus facilitating the episodic memory of 28 medical appointments, whilst also acting as an autobiographical memory of a particular time frame (in many cases, capturing up to 4 years of medical appointments). Referring to a previous appointment/s was now simple and straight forward.

The booklet has since been distributed by Cystic Fibrosis Ireland to every patient/carer within the Republic of Ireland (1,300 CF patients) in January 2019. In February 2020, hospitals within the NHS such as the Royal London Children's Hospital, in London, and Cambridge University Hospital, in Cambridge, also started the distribution of the check list to CF carers as an aid to memory recall *within* the medical appointment. Furthermore, the check list has gone to seven other countries for consideration/evaluation by their CF organisations. However, the impact of the check list booklet is best depicted by the mother of a 7-year-old CF child:

> "*We just wanted to say we received our medical appointment check list today, and we just wanted to say THANK YOU so much, we love it and it's going to be incredibly handy for us, although it's just a book to our little boy now, in a few years he'll know how great and simple it is as well*".

Design Principle

Two design principles emerged from the challenge of memory types and state:

DP 8. *To address a memory recall/information retrieval issue, one must understand and unpack declarative memory into its components and ensure that a design maps to "aid" the memory type drawn upon by the patient/carer within the medical appointment.*

DP 9. *A booklet of check lists should be created after the final design iteration, in order to efficiently facilitate patient/carer episodic and autobiographical memory recall/information retrieval of medical appointments.*

3.5.3.2. The Challenge of Capturing Emotional State

Design Issue

Patients with chronic conditions often have to alter their lives, dreams and career, where many patients (and indeed carers) mourn their illness and the impacts it has, or may have on their life (or the lives of others) before becoming adjusted to it (Turner, 2000). Others endure prolonged episodes of distress, often resulting in psychiatric disorders, such as depression or anxiety (Ibid). Schwabe and Wolf (2010) have described the negative effects that heightened emotional states can have on human cognitive abilities, such as deficient memory recall /information retrieval. Hence, it is clear why clinicians wish to know and understand the emotional state of their patients, yet interestingly in our study it was an adult CF patient (who had evaluated iteration 2) that pointed out the oversight in our check list, we had failed to allow the CF patient or carer to capture their emotional state. The challenge we faced was *how we might enable the capture of emotional state simply, but yet effectively?*

Course of Action

The design team were not surprised that there was a request to capture emotional state, on the other hand we were amazed that we had overlooked something so fundamental, given the fact that we had all experienced (albeit differently) the psychological burden of CF. Intrigued, we moved ahead and deliberated on how we might proceed. Looking to practice we began studying the PHQ-9 and GAD-7 questionnaires (often including Likert scales) which are in accordance with the new Cystic Fibrosis Foundation and European Cystic Fibrosis Society guidelines

(Quittner, 2016) and are used by CF clinics to screen patients for psychological symptoms.

We decided that given the fact that patients/carers were already familiar with such questionnaires that we would adopt aspects of them into our check list design. Nevertheless, as the check list was designed for CF patients/carers we wanted it to retain the earlier referenced sense of "*energetic and not excessively serious*". That is not to say that we were not taking the subject of mental health seriously, merely, that we did not want the check list to become (as expressed by one patient) "*another mind-numbing form*" that was somewhat detached from the user. On the contrary, we wanted the check list to incite personal reflection by the patient (*know thy self* - Socrates), to act as a source of personal inquiry, to ask "*how do I really feel?"* and "*what is making me feel this way"* (Figure 3-4)? We hoped that this personal self-examination would not only recreate a greater self-awareness amongst patients but also provoke CF patients to report how they felt to their clinicians, given the fact that they would now have this self-reflection in front of them in their medical appointment. Moreover, it is well established that self- observing, the deliberate act of self-examination, aids self-control in many diverse domains (Duckworth, 2019). For CF carers, it would of course be different, but nevertheless we hoped it would also stimulate inquiry into the emotional state of their CF child/children.

The result of this inclusion into the check list was somewhat mixed, a Senior Clinical Psychologist commented "*I think the smiley 'Likert' that you have currently is great to check in with present mood*". Coupled with this, nine of the eleven CF carers embraced and welcomed the introduction of the emotional state

section, since it got them to look beyond the physical manifestations of the disease, and to be more cognisant of their child's mental disposition. In contrast however, only four of the seven CF patients said they completed this section of the check list. Completing the Likert scale was not an issue for any of the seven patients, however the concern expressed by three CF patients lay in answering the question "*what is making you feel this way?"*. They deemed the answer to this question to be extremely private and felt that the check list in its current form was not physically secure enough to prevent family/others from gaining access (accidentally or otherwise) to their inner-most thoughts. While these three patients agreed that a section for emotional state in a check list is very important, they also concurred that the forum must guarantee information security. In counterpoint, the remaining four CF patients felt it was wonderful to have a medium to express their thoughts and more importantly to cause them to self-reflect. The issues around confidentiality were not a factor for them, they felt it was healthy to capture and share their feeling with others, to help them understand what it's like having CF, as articulated by one patient "*people need to know what it's like being me*".

Design Principle

The tenth design principle emerges from the of capturing emotional state and asserts:

DP 10. *It is important to encompass a mental health assessment into a medical appointment check list, in order for the patient to self-reflect and report on their emotional state within the medical appointment.*

3.6. Formalization of Learning

Drawing on principle 7 (generalized outcomes) in Figure 3-2. We move from the highly situated nature of our ADR project outcomes - the changes *within* the medical appointment as a result of the implementation of the check list, to the "*generic-and-abstract*" (Sein et al., 2011, p. 44). This entails, building on the problem instance (memory recall/information retrieval as a class of problem), and the generalisation of the solution instance, (a check list or aid to memory recall/information retrieval), to derive at 10 design principles. Shaped via the BIE cycles of the ADR project, these design principles were refined through reflection and learning. In essence, "*the design principles capture the knowledge gained about the process of building solutions for a given domain, and encompass knowledge about creating other instances that belong to this class*" (Sein et al., 2011, p.45).

The check list, including this set of DPs (DPs 7 to 8 being the most novel) is the concluding artefact and generalised knowledge output of this ADR research project. Table 3-4 (comprising of DPs 1 to 6) and Table 3-5 (consisting of the four most novel DPs 7 to 10) underscore the contributions to practice (both problem and solution) and theory (the Design Principles – classified by concept type) arising from this study. As one might expect, both tables also include theoretical context, linking the primary findings to the existing body of knowledge, positioning the contribution to knowledge and practice in the context of the research.

If we consider Figure 3-3 once more, we can see that we have abstracted the interaction of the various contexts of the research project. Where the model endeavours to encapsulate the amalgamation of diverse (yet related) environments

from which we extracted and processed knowledge during the course of the study. Not surprisingly, the model illustrates how the mainstay of our knowledge has come from medical appointment experiences in the form of practical knowledge, which has been complemented by the research project experience and empirical project-based learning in tandem with evidence garnered from extant literature. This integrative approach initiated and fuelled a collaborative sense-making amongst the design team, involving workshops, reflection deciphering and action. Finally, the model displays the DPs, which have emerged from the project as a contribution to aid others on their quest to create check lists for another distinct environment.

Table 3-4 Contributions to Theory and Practice - DPs 1 to 6

Contribution to Theory		Concept Type	Contribution to Practice		Context
No.	**Design Principle**		**Problem**	**Solution**	**Theoretical/Practical**
DP1	In order to ensure the successful design of a check list for use by patients/carers within the medical appointment, one must have a **clear understanding** of the check **lists' function** within the appointment.	**Function**	Bringing to light the challenges of understanding exactly what a data artefact intended function or purpose is going to be - What data is important within the medical appointment. Who the data is important to? When it the data important to them? Why the data is significant to these stakeholders? Where is the data important?	How Action Design Research in conjunction with design thinking can be used effectively to develop a check list with a clearly defined function - to aid memory recall, reduce stress and increase empowerment within the medical appointment.	This concurs with Simmons & Chew, (2015), Schwesinger, (2010), and Gawande, 2010) who state clear and concise objective/function are paramount to success. We have extended this principle *"Utilitas*" or function into a new environment from the perspective of a new/under represented stakeholder (the patient/carer).
DP2	It is essential to focus on the **vital detail**s that the patient/carer **struggle to remember**, but are **essential to recall/capture** within the medical appointment.	**Information Retrieval/ Memory Recall** Function	Underscoring the challenge of deciding/identifying the essential medical information that a patient/carer needs to remember/capture within the medical appointment?	Analysis of appointment narratives, identified the "killer items" that must be included in a medical appointment check list, medical data that patients/carers not only struggle to remember, but also have to recall /capture.	This coincides with Jansen (2008) who contends that to improve understanding and recall, one needs to be explicit, prioritise and encapsulate the major data points. However, we have extended same to the medical appointment setting, identifying what we refer to as the *"killer items"* to be remembered/ captured to satisfy the needs of the patient/carer.

Table 3-4 continued …

No.	Design Principle		Problem	Solution	Theoretical/Practical
DP3	**Categorise data elements** according to **emergent sections**, arising from the **analysis of narrative patterns** within the medical appointment, with **elements grouped** as **expected** and **understood** by the patient/carer.	**Categorisation** Form	Highlights the challenge and need to categorise medical data elements within an artefact to address memory recall/information retrieval within the medical appointment.	A check list with categorised/clustered data elements that patients/carers not only instantly recognise, but that also clearly communicate the design's function and intent i.e., categorised according to narrative patterns within the medical appointment.	This agrees with Kessels, (2003), Safeer (2005) and Miller (1956) who maintain that explicit categorisation increases memory recall. We have applied this thinking into a new check list as an aid to memory recall/information retrieval within the medical appointment, categorising data as expected by users (patients/carers), according to the narrative patterns therein.
DP4	**Structure** the check list **according to the workflow** of a medical appointment, with **elements** sequentially aligned **as required**, **understood** and **anticipated** by the patient/carer.	**Structure** Form	Provokes a sense of the need and challenges involved when deciding/identifying the most suitable and effective structure to put on medical data that needs to be recalled/ captured medical appointment.	A check list which is structured according to the workflow of the medical appointment, with elements sequentially aligned as required, understood and anticipated by the patient/carer within their medical appointment.	In this DP regarding the check lists structure, we have merged knowledge from two different fields, 1) cognition, where the structuring of information augments human comprehension, and aids memory recall/information retrieval (Ackermann et al., 2016; Mandler, 1967), and 2) medical, where we considered/applied learnings from the clinical workflow of the medical appointment (Sarkar et al. (2011), so that the check list structure would work within the appointment, and be familiar to the patient/carer.

Table 3-4 continued …

No.	Design Principle		Problem	Solution	Theoretical/Practical
DP 5	A check list should be **paper - based**, in order to **avoid interfering** with the **critical medical discourse** between the patient/carer and the doctor within a medical appointment. **Note this DP may change with time. **	**Usability**	Underlines the challenges of placing an artefact within the medical appointment, where it is imperative that the object avoids interfering with the critical medical discourse between the patient/carer and the doctor?	A paper-based check list design, that aids memory recall/information retrieval, and yet escapes getting in the way of the vital medical dialogue between the patient/carer and the doctor?	*"The focus on aesthetics may blind the designer to the lack of usability"* (Norman, 2013, p.98). This DP centres on the choice/recommendation of a paper based (versus a digital) artefact. Here usability (Norman, 2013) and the vital dialogue between patient/carer and the doctor (Martin et al., 2014), are key considerations, as the check list cannot detract from the patient/carer/doctor experience (Johnson & Finn, 2017) nor interfere in the medical dialogue (Martin et al., 2014).
DP6	**Language** in a medical appointment check list must be **concise**, and yet **clearly understood** by the patient/carer.	**Language** Form	Highlights the various challenges around the use of language when designing an artefact to aid memory recall/information retrieval for patients/carers within medical appointment. Such as (1) brevity (including abbreviations & tasks) - must be understandable and unambiguous. (2) phraseology simple but yet clearly understood. (3) Serve as cues to aid memory recall.	A check list for use by patients/carers within the medical appointment targeting the reading level of those with a lower educational background. Displaying brevity (essential), it nevertheless uses plain concise language that is clearly understood and acts as actual memory recall/information retrieval cues for the patient/carer.	Building on the works of Ley, (1988) regarding and the importance of comprehension of imparted health information, and Martin et al., (2014) ref health literacy and clinical outcomes, we have analysed narratives, conducted workshops and interviews, and have arrived at a set of terms for the check list within the medical appointment that are succinct and yet clearly understood by users (*"living room language"* - Davis et al., 2002) and doctors (a shared lexicon (Doak et al., 1996; 1998).

Table 3-5 Most Novel Contributions to Theory and Practice DP 7 to 10

Contribution to Theory		Concept Type	Contribution to Practice		Context
No.	**Design Principle**		**Problem**	**Solution**	**Theoretical/Practical**
DP7	The **correct use of colour** is vital within a well-designed check list to **facilitate memory recall/information retrieva**l and to draw the patients'/carers' **attention**.	**Information Retrieval/Memory Recall** Function **,Usability & Colour** Form	Underlines some of the challenges encountered by patients/carers when endeavouring to use a memory recall/ information retrieval device reported within the medical appointment, such as stress, distractions and focus etc.	A check list to address memory recall/information retrieval within the medical appointment, using the correct blend of colour to engender a greater degree of distinction, enhance readability and user experience. The check list colour palette aids the design, ensuring it functions aesthetically while also meeting the objectives of augmented attention, memory, tone and feeling?	Contrary to the advice Gawande, (2010), who caution against the use of colour in check lists. We advocate for the correct use of colour within a check list for use as a memory recall aid within the medical appointment, and to draw a user's attention to categories/sections of the check list. The medical appointment can be a stressful and distracting environment (Turner, 2000). On the other hand, from a cognitive perspective colour, takes hold of attention, via visual stimuli, where an entity can seizes our interest (Bundesen et al., 2005; Wolfe, 1994). Moreover, the human eye is organised to emphasise the perception of edges and contrast (Maiochhi, 2015, p.30). Additionally, the more thought given to a tangible stimulus the greater the likelihood that an entity will be encoded in long-term memory storage (Sternberg et al., 2009).

Table 3-5 continued …

No.	Design Principle		Problem	Solution	Theoretical/Practical
DP 8	To address a memory recall/information retrieval issue, one must understand and **unpack declarative memory** into its **subcomponents**, and ensure that a design **maps to "aid" the memory type** drawn upon by the patient/carer within the medical appointment.	**Information Retrieval/ Memory Recall** Function	Elicits a real appreciation amongst stakeholders for the need to unravel the various memory types used within the medical appointment when addressing the issue of poor memory recall/information retrieval amongst patients/carers.	As a solution the check list highlights the significance of mapping to "aid" the memory type drawn on *during* the doctor patient discourse within the medical appointment.	To date we have not encountered any paper that has looked at check list design through the lens of long-term declarative memory. We strongly advise same as information retrieval/memory recall observed in patients *during* the *elicitation* phase is very often episodic in nature where one must recall specific details of events including those outside of the appointment setting (Martin et al., 2014). Autobiographical memory builds on episodic accounts, taken together make up a person's autobiographical memory or medical history (Habermas & Bluck 2000, McAdams 2001). For patients with chronic conditions the details of similar recurrent events can often seem to almost merge into one another (Rubin et al., 2015). Not surprisingly then, autobiographical memory has a high probability of being in error, where dating is found to be based on inference, estimation and guesswork (Brown et al., 1986). Hence this new DP is critical to the success of a check list to aid memory recall/ information retrieval within the medical appointment.

Table 3-5 continued …

No.	Design Principle		Problem	Solution	Theoretical/Practical
DP9	A **booklet of check lists** should be created after the final design iteration, in order to efficiently **facilitate** patient/carer **episodic** and **autobiographical memory recall/information retrieval** of medical appointments.	**Information Retrieval/ Memory Recall** Function	Provokes a real sense of the challenges of memory recall/ information retrieval for a patient/carer ranging from particular events (episodic), to remembering to carry out various actions (prospective memory), to an autobiographical memory account of their/patients individual health journey.	The professional, physically robust check list booklet, demonstrates how one can create a repository of medical discourse, facilitating episodic memory of medical events, also serving as a memory aid to carrying out actions (adherence), whilst also acting as an autobiographical memory of a particular time frame.	A patient's medical history is both episodic and autobiographical in nature (Cohen et al., 1995), and so taking this into account, we advocate that a booklet of check list be created to facilitate both types of declarative long-term memory. This is new and we have not seen same in any research published to date in check list design, or indeed in memory recall aids within the medical appointment. Additionally, we encourage the creation of a booklet of check lists as the human codification process also occurs through the relationship of that information to the medium itself (Schwesinger, 2010). The check list in this study is also robustly designed to sit firmly on a patients/carers lap (note tables are not usually supplied to patients/carers within appointment settings), hence adding to usability and ease of use. This is also new and previously not reported in literature. Interesting, having the check list spread across two pages goes against Weiser et al.'s (2010) advice of keeping a check list to one page.

Table 3-5 continued …

No.	Design Principle		Problem	Solution	Theoretical/Practical
DP10	It is important to encompass a **mental health assessment** into a medical appointment check list, in order for the patient to **self-reflect** and **report** on their emotional state within the medical appointment.	**Function**	Highlights the requirement for an object to help patients /carers to reflect on and report on their/patients mental health status within the medical appointment.	The solution stimulates reflection/reporting by the patient/carer, to act as a probe of mental health status, to ask "how do I/patient really feel?" and "what is making me/patient feel this way".	Stress effects our ability to remember and has significant associations between physical and mental health (Quinter et al., 2016; Kessels, 2003; Jansen, 2008; Safeer, 2005; Ley, 1979)). The very context of the medical appointment itself act as a source of stress to both patient and carers, making doctor-patient communication challenging (Ong et al., 1995). This DP is new and we have not seen same in any check list design literature published to date, or indeed in memory recall aids within the medical appointment. Additionally, we encourage the inclusion of this DP as it's well established that self-observing, the deliberate act of self-examination, aids self-control in many diverse domains (Duckworth, 2019) and to facilitate a doctor to screen patients for psychological symptoms.

3.7. Concluding Remarks

Designing a check list that is adapted to the needs of patients *within* the medical appointment is complex. However, the ten key DPs found in this study can be used to inform the design of a patient-centred artefact that specifically addresses the challenges of memory recall *within* two key information phases (*elicitation* and *elucidation*) of the medical appointment.

Bringing our paper to a close and by way of summary, we depict our 10 DPs through a *People, Process, Technology, Data* lens in Table 3-6 (DPs 1 to 6) and Table 3-7 (DPs 7 to 10 – for our most original DPs). While the emergent design principles inform the creation of a check list for CF patients/carers, they may also be valid in the creation of other innovations aimed to aid memory recall, augmenting both the quality of data captured (for use *after* the medical appointment) and imparted to the doctor for diagnostic decision-making purposes.

Future directions include the digitisation of the check list, to investigate/validate the possibility of using same *within* the medical appointment. A solution that would aid memory recall/information retrieval and yet advance the current paper-based check list. We have no doubt that many challenges lie ahead in this ADR endeavour, not least the avoidance of any interreference in the doctor patient dialogue, vital *within* this vastly complex medical setting.

Table 3-6 Summary of DPs 1-6 through a People, Process, Technology, Data lens

No.	Concept Type	People	Process	Technology	Data
DP6	Language [Form]	Patients/ carers	Elicitation & elucidation phases.	1.) **Plain concise** language - improves **comprehension** and **memory recall/information retrieval**. 2.) Acts as **retrieval cue**.	Medical History
		Doctor	Elicitation & elucidation phases.	Augments **data quality/capture** [(by patient/carer)].	Diagnostic information
DP 5	Usability	Patients/ carers	Elicitation & elucidation phases.	**Avoid interference** - **vital** medical dialogue between the patient/carer and the doctor	Medical History
		Doctor	Elicitation & elucidation phases.	Tool **does not delay** the doctor/discourse in the medical appointment (and yet augments **data quality/capture).** [-by the patient/carer]	Diagnostic information
DP4	Structure [Form]	Patients/ carers	Elicitation & elucidation phases.	1.) **Aids memory recall/information retrieval.** 2.) **Structured** to the **workflow** of the medical appointment. 3.) Elements **sequentially aligned**. 4.) As **understood and anticipated**.	Medical History
		Doctor	Elicitation & elucidation phases.	Augments **data quality/capture** [(by patient/carer).]	Diagnostic information
DP3	Categorisation [Form]	Patients/ carers	Elicitation & elucidation phases.	1.) Improves **memory recall/information retrieval**. 2.) **Categorised** according to **narrative patterns**. 3.) Instantly **recognisable**. 4.) **Communicates** the **function** and **intent.**	Medical History
		Doctor	Elicitation & elucidation phases.	Augments **data quality/capture**. [(by patient/carer)]	Diagnostic information
DP2	Information Retrieval/Memory Recall [Function]	Patients/ carers	Elicitation & elucidation phases.	1.) Edifies **brevity.** 2.) Take **memory capacity** factors into account. 3.) Helps **memory recall/information retrieval.**	Medical History
		Doctor	Elicitation & elucidation phases.	Augments **data quality/capture**. [(by patient/carer)]	**Key** Diagnostic information
DP1	Function	Patients/ carers	Elicitation & elucidation phases.	**Function is clear** and **easily understood** with **clear instruction** where required.	Medical History
		Doctor	Elicitation & elucidation phases.	Augments **data quality/capture**. [(by patient/carer)]	Diagnostic information

Table 3-7 Summary of most novel DPs 7-10 through a People, Process, Technology, Data lens

No.	Concept Type	People	Process	Technology	Data
DP7	Information Retrieval/Memory Recall [Function] ,Usability & Colour [Form]	Patients/ carers	Elicitation & elucidation phases.	1) Aids **memory recall/information retrieval**. 2.) Augments **attention**.	Medical History
		Doctor	Elicitation & elucidation phases.	Augmented **data quality/capture**. [(by patient/carer)]	Diagnostic information
DP 8	Information Retrieval/Memory Recall [Function]	Patients/ carers	Elicitation & elucidation phases.	Maps to "**aid**" **memory type** used.	Medical History.
		Doctor	Elicitation & elucidation phases.	Augmented **data quality /capture.** [(by patient/carer)]	Diagnostic information.
DP9	Information Retrieval/Memory Recall [Function]	Patients/ carers	Elicitation & elucidation phases - **over time**.	Booklet facilitates **episodic /autobiographic memory** recall/information retrieval.	A **repository** of medical discourse /history - **time dated.**
		Doctor	Elicitation & elucidation phases - **over time**.	Augmented **data quality/capture over time** [(by patient/carer)].	**Rich temporal** diagnostic information.
DP10	Function	Patients/ carers	1.) Reflection [(before apt.)]. 2.) Elicitation phase.	**Reflect on** and **report** on patient **mental health status**.	Mental health status/history
		Doctor	Elicitation phase.	**Reporting** [by patient/carer] on patient **mental health** status.	Diagnostic information

3.8. References

Ackermann, S., Ghanim L., Heierle A., Hertwig R., Langewitz W., Mata R. & Bingisser R. (2016) Information structuring improves recall of emergency discharge information: a randomized clinical trial, Psychology, *Health & Medicine*, 22:6, 646-662.

Arias, E., Eden, H., Fisher, G., Gorman, A. & Scharff, E. (2000) Transcending the Individual Human Mind - Creating Shared Understanding Through Collaborative Design. *ACM Transactions on Computer-Human Interaction*, 7, 84-113.

Arriaga, A., Bader M., Wong J., Lipsitz S., Berry W., Ziewacz J., Hepner D., Boorman D., Pozner C., Smink D., Gawande A., (2013*). N Engl J Med* 2013; 368:246-253 January 17.

Borchard, A, Schwappach DL, Barbir A, Bezzola P. A Systematic Review of the Effectiveness, Compliance, and Critical Factors for Implementation of Safety Checklists in Surgery. (2012). *Annals of Surgery*, Volume 256, Number 6.

Brown, A. D., Stacey, P. & Nandhakumar, J. (2008). Making Sense of Sense-making Narratives. *Human Relations*, 61, 1035-1062.

Bundesen, Claus, Habekost, Thomas, Kyllingsbæk, Søren. (2005). A neural theory of visual attention: bridging cognition and neurophysiology. *Psychological Review*, Vol 112(2), 291-328.

Cohen, Gillian, and Rosalind Java. (1995). "Memory for Medical History: Accuracy of Recall." *Applied Cognitive Psychology* 9 (4): 273–88.

Cox, R. & Brna, P. (1994) Supporting the Use of External Representations in Problem Solving: The Need for Flexible Learning Environments. *AAI/AI-ED Technical Reports*, No. 102.

Cramer, J. A (1991). Identifying and improving compliance patterns. In J. A. S. Cramer B. (Ed.), Patient compliance in medical practice and clinical trials (pp. 387–392). New York: Raven Press.

Cross, N. (2006). *Designerly Ways of Knowing*: Springer.

Cuthill, I. C., Hunt, S., Cleary, C., and Clark, C. (1997). Colour bands, dominance, and body mass regulation in male zebra finches (Taeniopygia guttata). *Proc. R. Soc. B Biol. Sci.* 264, 1093–1099.

Danziger, K. (2008). *Marking the Mind*. Cambridge: Cambridge University Press.

Davis, T. C., Williams, M. V., Marin, E., Parker, R. M. and Glass, J. (2002), Health Literacy and Cancer Communication. CA: *A Cancer Journal for Clinicians*, 52: 134-149.

Dennis, A. R. 2001. "Relevance in Information Systems Research," *Communications of the Association for Information Systems* (6), pp. 40-42.

Doak, C. C., Doak, L. G., Friedell, G. H., & Meade, C. D. (1998). Improving comprehension for cancer patients with low literacy skills: Strategies for clinicians. CA: *A Cancer Journal for Clinicians*, 48 (3), 151–162.

Doak, C. C., Doak, L. G., & Root, J. (1996). *Teaching patients with low literacy skills* (2nd ed.). Philadelphia: J. B. Lippincott.

Dreiskaemper, D., Strauss, B., Hagemann, N., and Büsch, D. (2013). Influence of Red jersey color on physical parameters in combat sports. *J. Sport Exerc. Psychol*. 35, 44–49.

Duckworth A., (2019) Self-Reports Spur Self-Reflection. *MIT Sloan Mgt. Review*. 60 (3):14-16.

Einstein, G. O., & McDaniel, M. A. (1990). Normal aging and prospective memory. *Journal of Experimental Psychology: Learning, Memory, & Cognition*, 16, 717–726.

Elliot, A. J., and Maier, M. A. (2014). Color psychology: effects of perceiving color on psychological functioning in humans. *Annu. Rev. Psychol*. 65, 95–120.

Eysenck, MW. (2009) *Fundamental of psychology*. London (UK): Psychology Press.

Farley, FH, Grant AP. Arousal and cognition: Memory for color versus black and white multimedia presentation. *J Psychol*. 1976;94(1):147–150.

Federal Aviation Administration, (2016) Handbook. https://www.faa.gov/regulations_policies/handbooks_manuals/aviation/phak/media/pilot_handbook.pdf

Gawande, A. (2010). *The checklist manifesto: How to get things right*. New York: Metropolitan Books.

Gioia, D. A. & Chittipeddi, K. (1991). Sense-making and Sensegiving in Strategic Change Initiation. *Strategic Management Journal*, 12, 433–448.

Gregor, S., & Hevner, A. (2013). Positioning and presenting design science research for maximum impact". *MIS Quarterly*, 37(2), 337–355.

Haj-Bolouri, A., Bernhardsson L., Rossi M. (2016) Padre: *A Method for Participatory Action Design Research*. In: Parsons J., Tuunanen T., Venable J., Donnellan B., Helfert M.,

Hales, B., Terblanche M., Fowler R., Sibbald W., (2008) Development of medical checklists for improved quality of patient care, *International Journal for Quality in Health Care*, Volume 20, Issue 1, Pages 22–30.

Hampton, J. R., Harrison, M. J., Mitchell, J. R., Prichard, J. S., & Seymour, C. (1975). Relative contributions of history-taking, physical examination, and laboratory investigation to diagnosis and management of medical outpatients. *British Medical Journal*, 2(5969), 486–489.

Henig, R., (2016). The Hospital Checklist: How Social Science Insights Improve Health Care Outcomes. https://www.nap.edu/read/23510/

Hevner, A. R., March, S. T., Park, J. & Ram, S. (2004) Design Science in Information Systems Research. *MIS Quarterly*, 28, 75-105.

Hevner, A. (2007). "A Three Cycle View of Design Science Research," *Scandinavian Journal of Information Systems* (19:2), pp. 87-92.

Hustad, E. and Olsen D. H. (2014), Educating reflective Enterprise Systems practitioners: a design research study of the iterative building of a teaching framework, *Info Systems J*, 5, pages 445–473.

Iivari, J. (2015). Distinguishing and contrasting two strategies for design science research. *European Journal of Information Systems*, 24(1), 107–115.

James, JT. (2013). A new, evidence-based estimate of patient harms associated with hospital care. *J Patient Saf* 9:122–8.

Jansen, J, van Weert J, van der Meulen N, van Dulmen S, Heeren T, Bensing J. (2008) Recall in older cancer patients: measuring memory for medical information. *Gerontologist*, 48(2):149-57.

Jansen, J, Butow PN, van Weert JC, van Dulmen S, Devine RJ, Heeren TJ, Bensing JM, Tattersall MH. (2008) Does age really matter? Recall of information presented to newly referred patients with cancer. *J Clin Oncol*. 26:5450-7.

Japp, A., Robertson, C., Wright, R., Reed. M., Robson, R., (2018). *Macleod's Clinical Diagnosis*. 2nd Edition. Elsevier.

Kassirer, JP. (1983) Teaching clinical medicine by iterative hypothesis testing. Let's preach what we practice. *N Engl J Med*.309(15):921-923.

Kaya, N., and Epps, H. (2004). Relationship between color and emotion: a study of college students. *Coll. Stud. J*. 38, 396–405.

Kessels, R., (2003) Patients' memory for medical information. *J R Soc Med* 96:219–222.

Keijzer-Broers, W., Florez-Atehortua, L., & de Reuver, M. (2016). Prototyping a health and wellbeing platform: An action design research approach. *In Proceedings of the 2016 49th Hawaii International Conference on System Sciences* (pp. 3462–3471). IEEE.

Klein, H.K., & Myers, M.D. (1999) A Set of principles for conducting and evaluating interpretive field studies in information systems. *MIS Quarterly*, 23(1), 67–93.

Kvale, S., & Brinkmann, S. (2009) *Interviews: Learning the Craft of Qualitative Research Interviewing*. Sage, Los Angeles, Calif.

Lazare A., Putnam S.M., Lipkin M. (1995) *Three Functions of the Medical Interview*. In: Lipkin M., Putnam S.M., Lazare A., Carroll J.G., Frankel R.M. (eds) The Medical Interview. Frontiers of Primary Care. Springer, New York, NY.

Leape, L.L. (2014). The Checklist Conundrum. *New England Journal of Medicine*, 370, 1063-1064.

Lee, A. S. (1991) Integrating Positivist and Interpretive Approaches to Organizational Research. *Organization Science*, 2, 342-365.

Lee, A. S. (1994) Electronic Mail as a Medium for Rich Communication: An Empirical Investigation using Hermeneutic Interpretation. *MIS Quarterly*, 18, 143-157.

Ley, P. (1979). Memory for medical information. *British Journal of Social and Clinical Psychology*, 18, 245–255.

Ley, P. (1988). *Communicating with patients: Improving communication, satisfaction, and compliance*. New York: Croom Helm.

Lidwell, W. (2003). *Universal Principles of Design*. Rockport Publishers.

Logan, V. (2017) Information as a Second Language: Enabling Data Literacy for Digital Society. https://www.gartner.com/doc/3602517/information-second-language-enabling-data.

Mandler, G. (1967). *Organization and memory*. In K. W. Spence and J. T. Spence (Eds.), The Psychology of Learning and Motivation. New York: Academic Press.

March, S. T. & Smith, G. F. (1995) Design and Natural Science Research on Information Technology. *Decision Support Systems*, 15, 251-266.

Martin L., Dimatteo M. (2014) *The Oxford Handbook of Health Communication, Behaviour Change, and Treatment Adherence*. Oxford University Press.

Mazza, R. & Berre, A. (2007) Focus Group Methodology for Evaluating Information Visualization Techniques and Tools. *11th International Conference of Information Visualization.* Zürich, Switzerland.

McAdams, D. (2003) "Identification and codification of principles for functional tolerance design," *Journal of Engineering Design*, vol. 14, pp. 355-375.

McGuire, L. C. (1996). Remembering what the doctor said: Organization and older adults' memory for medical information. *Experimental Aging Research*, 22, 403–428.

McPherson, M. L., Smith, S. W., Powers, A., & Zuckerman, I. H. (2008). Association between diabetes patients' knowledge about medications and their blood glucose control. *Research in Social and Administrative Pharmacy*, 4, 37–45.

Mika, V. S., Wood, P. R., Weiss, B. D., & Treviño, L. (2007). Ask Me 3: Improving communication in a Hispanic paediatric outpatient practice. *American Journal of Health Behavior*, 31 (Suppl 1), S115–S121.

Miller, G. A. (1956). The magical number 7, plus or minus 2 – Some limits on our capacity for processing information. *Psychological Review*, 63, 81–97.

Morrow, D. G., Leirer, V. O., & Altieri, P. A. (1992). Aging, expertise, and narrative processing. *Psychology and Aging*, 7(3), 376-388.

Maiochhi, M., (2015). *The neuroscientific basis of successful Design, How Emotions and perceptions matter.* Springer.

Mustafa, M.I., Sjöström J. (2013) *Design Principles for Research Data Export: Lessons Learned in e-Health Design Research*. In: vom Brocke J., Hekkala R., Ram S., Rossi M. (eds) Design Science at the Intersection of Physical and Virtual Design. DESRIST 2013. Lecture Notes in Computer Science, vol 7939. Springer, Berlin, Heidelberg

Nikolov, A., (2017) Design principle: Consistency. https://uxdesign.cc/design-principle-consistency-6b0cf7e7339f [last visited 29/11/2018]

Ong, L. M., de Haes, J. C., Hoos, A. M., & Lammes, F. B. (1995). Doctor–patient communication: A review of the literature. *Social Science & Medicine*, 40, 903–918.

O'Raghallaigh, P. (2011) Designing an Innovation Modelling Tool to Support Practitioners in the Building of Interactive Theory. A Thesis Submitted for the Degree of Doctor of Philosophy of the National University of Ireland. (unpublished)

Pan, Y. (2012) Attentional capture by working memory contents. *Can J Exp Psychol*. 64(2):124–128.

Paasche-Orlow, M. K., Parker, R. M., Gazmararian, J. A., Nielsen-Bohlman, L. T., & Rudd, R. R. (2005). The prevalence of limited health literacy. *Journal of General Internal Medicine*, 20, 175–184.

Personal Injury Team Ireland (2017). Medical Negligence in hospitals in Ireland.

http://www.personalinjuryireland.ie/medical-negligence-in-hospitals-in-ireland.

Pronovost, M. A.R.A.P.J. (2014) Advancing the use of checklists for evaluating performance in health care. *Academic Medicine*, 89, 1-3.

Pryke, S. R., Astheimer, L. B., Buttemer, W. A., and Griffith, S. C. (2007). Frequency dependent physiological trade-offs between competing colour morphs. *Biol. Lett.* 3, 494–497.

Pryke, S. R. (2009). Is red an innate or learned signal of aggression and intimidation? *Anim. Behav*. 78, 393–398.

Quittner AL, Saez-Flores E, Barton JD. (2016). The psychological burden of cystic fibrosis. *Curr. Opin. Pulm. Med*. 22(2):187–91.

Radvansky, G, (2017) *Human Memory*. 3rd Edition. Taylor & Francis.

Redman, T. (2016) Assess Whether You Have a Data Quality Problem Harvard Business Review. https://hbr.org/2016/07/assess-whether-you-have-a-data-quality-problem

Ricoeur, P. (1984) *The Reality of the Historical Past*, Milwaukee, WI., USA, Marquette University Press.

Rogerson, C., Scott E. (2014). Motivating an action design research approach to implementing online training in an organisational context. *Interact Technol Smart Educ* 11:32-44.

Rosen, M., Pronovost P., (2014) Advancing the Use of Checklists for Evaluating Performance in Health Care, *Academic Medicine*, Vol. 89, No. 7.

Rubin, D., Umanath S., (2015) Event Memory: A Theory of Memory for Laboratory, Autobiographical, and Fictional Events. *Psychol Rev*. 122(1): 1–23.

Safeer, RS, Keenan J. (2005). Health literacy: the gap between physicians and patients. *Am Fam Physician* 72:463-8.

Sandler, G. (1980). The importance of the history in the medical clinic and the cost of unnecessary tests. *Am Heart J.* Dec;100(6 Pt 1):928-31

Sarkar, U., Schillinger D., Bibbins-Domingo K., Nápoles A., Karliner L., Pérez-Stable E.,

(2011) Patient–physicians' information exchange in outpatient cardiac care: Time for a heart to heart? *Patient Education and Counseling*, Volume 85, Issue 2, Pages 173-179.

Schraa, J., Dirks J., (1982) Improving patient recall and the comprehension of the treatment regime. *Journal of Asthma*, 19(3), 159162.

Schon, D. A. (1983). *The reflective practitioner: How professionals think in action* (Vol. 5126). New York: Basic books.

Schwabe, L., & Wolf, O. T. (2010). Learning under stress impairs memory formation. *Neurobiology of Learning and Memory*, 93, 183–188.

Schwabe, L., Wolf, O. T., & Oitzl, M. S. (2010). Memory formation under stress: Quantity and quality. *Neuroscience and Biobehavioral Reviews*, 34, 584–591.

Schwartzberg, J. G., VanGeest, J., & Wang, C. (Eds.). (2005). Understanding health literacy: Implications for medicine and public health. Chicago: American Medical Association.

Schwesinger, B., (2010). The Form Book, Best Practice in Creating Forms for printed and online use. Thames & Hudson.

Semel, ME, Resch S, Haynes AB, Funk LM, Bader A, Berry WR., Weiser TG., Gawande AA. (2010). Adopting a surgical safety checklist could save money and improve the quality of care in US hospitals. *Health Aff* (Millwood). 29(9):1593-9.

Sein, M., Henfridsson, O., Purao, S., Rossi, M., & Lindgren, R. (2011) Action design research. *MIS Quarterly*, 35(1), 37–56.

Sibbald, M., de Bruin, A.B.H., Yu, E., van Merrienboer JJ. (2015). Why verifying diagnostic decisions with a checklist can help: insights from eye tracking. Adv in *Health Sci Educ*.20: 1053.

Simmons, M., Chew I., (2015) How to Create A Checklist. http://www.beseminal.com/wp-content/uploads/2015/11/HowToCreateAChecklistFinal.pdf [Site Last visited 29/11/2018].

Solet, DJ, Norvell JM, Rutan GH, Frankel RM. (2005). Lost in translation: challenges and opportunities in physician-to-physician communication during patient handoffs. *Acad. Med* 80:1094–9.

Sternberg, RJ. (2009) *Cognitive Psychology*. 5th Ed. Belmont (BE): Wadsworth Cengage Learning.

Stock, C., Sundt T., Timeout for Checklists? (2015) *Annals of Surgery* _ Volume 261, Number 5.

Taylor, J. R. & Van Every, E. J. (2000) *The Emergent Organization: Communication as its Site and Surface*, Mahwah, NJ., USA, Lawrence Erlbaum.

Turner, J., & Kelly, B. (2000). Emotional dimensions of chronic disease. Western Journal of Medicine, 172(2), 124–128.

Twomey, M., Sammon, D., Nagle, T. and O'Raghallaigh, P. (2018) 'A check list designed to improve memory recall amongst CF patients', *ECIS 2018: Twenty-Sixth European Conference on Information Systems*, Portsmouth, UK, 23-26 June.

US Dept. of Health and Human Services. (2019) The Healthy People 2020. https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-health/interventions-resources/health-literacy.

Verdaasdonk, E.G., Stassen, L.P.S., Widhiasmara, P.P., Dankelman J. (2009) Surg Endosc 23: 715.

Vitruvius, Pollio. transl Morris Hicky Morgan (1960) The ten books on architecture. Courier Dover Publications.

Watson, PW, McKinstry B., (2009). A systematic review of interventions to improve recall of medical advice in healthcare consultations. *J R Soc Med*, 102:235-43.

Weick, K. E. (2005) *The Experience of Theorizing: Sense-making as a Topic and Resource*. IN SMITH, K. G. & HITT, M. A. (Eds.) Great Minds in Management: The Process of Theory Development. Oxford, UK., Oxford University Press.

Weiser, T.G., Haynes A.B., Lashoher A., Dziekan G., Boorman D.J., Berry W.J., Gawande A.A., (2010). Perspectives in quality: designing the WHO Surgical Safety Checklist, International *Journal for Quality in Health Care*, Volume 22, Issue 5, 1, Pages 365–370.

Wichmann, F. A., Sharpe, L. T., and Gegenfurtner, K. R. (2002). The contributions of color to recognition memory for natural scenes. *Journal of Experimental Psychology: Learning, Memory, and Cognition*, 28(3), 509–20.

Wieringa, R. (2010) Relevance and Problem Choice in Design Science. *The 5th International Conference on Design Science Research in Information Systems and Technology (DESRIST*). St. Gallen, Switzerland.

Wolfe, J. M. (1994). Guided Search 2.0: a revised model of visual search. *Psychonomic Bulletin & Review*, 1, 202–38.

World Health Organisation. (2009) A Surgical Safety Checklist to Reduce Morbidity and Mortality in a Global Population. http://www.who.int/patientsafety/safesurgery/Surgical_Safety_Checklist.pdf

World Health Organisation. (2010) New scientific evidence supports WHO findings: a surgical safety checklist could save hundreds of thousands of lives. Available from: http://www.who.int/patientsafety/safesurgery/checklist_saves_lives/en/.

Chapter Four

4. Discussion and Conclusion

4.1 Introduction

This chapter presents the overall conclusions of my research study. I open with a recapping of the research aim and the various research objectives for my investigation. This is followed by a concluding dialog on each objective in the research. The next section concisely re-examines the outcomes of the study, focusing on the contributions to: (1) knowledge and (2) practice. Thereafter, in the penultimate section, I assess the limitations of the research, followed by a brief discussion on future areas of enquiry. The chapter closes with my concluding remarks and thoughts. Therefore, the aim of this chapter is to *appraise the research conclusions with reference to their implications and importance to both knowledge and practice, whilst identifying future research directions in tandem with the limitations of the study.*

4.2 Overview of Research

As we have seen in early chapters the medical appointment (sometimes referred to as the medical interview) is a complex environment, embracing an interpersonal process between doctor and patient/carer, engaging in a bidirectional discourse, in which information (the raw material) is evoked and exchanged. It is important to appreciate that central to the discipline of the medical appointment is the concept of "*making a diagnosis*" (Lazare, 1995), or determining the health difficulty that a

patient exhibits *within* the medical appointment. While at first glance this may sound simple, the process of formulating a diagnosis is quite challenging. Metaphorically speaking, it is akin to assembling a jigsaw, in that it is a progressive decision-making process, developed from key data components, requiring doctors to ratify their diagnostic verdicts, by reflecting *'in practice',* revising decisions dynamically, in real-time (Schön, 1983; Sibbald et al., 2015). In previous chapters we ascertained that one of the most important data components required for a diagnosis is a patients' medical history, an intricate medical autobiography, embodying the patient's accumulated health journey, infused with several intermittent medical appointments. Not surprisingly then, the ability of the patient/carer to recall medical history becomes paramount to the very success of the medical encounter, that and of course the ability of the patient/carer to remember what has been imparted *within* the medical appointment.

The research aim guiding this study was to answer the question: '*How might we augment Cystic Fibrosis (CF) patient/carer memory recall/information retrieval within the elicitation phase and elucidation phase of the medical appointment?*'

In order to address this research aim, a number of research objectives were seen as being pivotal to the research undertaking, and so these are now reiterated in Table 4-1. We will now visit each in turn and discuss and reflect on same.

Table 4-1 Research Objectives Guiding This Study

Demonstrated in Output	Objective	Question Type	Question	Complete
Papers 1-5	**1**	**Why?**	Explain why memory recall/information retrieval is so important *within* the context of the medical appointment?	**Y**
Paper 1, Paper 4, Paper 5	**2**	**How?**	Rationalise the research paradigm, methods, and techniques appropriate to the research objective.	**Y**
Paper 1	**3**	**What?**	Develop a pretotype in the form of a check list that aids CF patients /carers memory recall *within* the medical appointment environment.	**Y**

4.2.1 Objective One

Explain why memory recall/information retrieval is so important *within* the context of the medical appointment?

On the question of the importance of memory recall/information retrieval *within* the medical appointment, Peterson et al. (1992) report that 76% of a patient's medical history informs the final diagnosis. In Paper 4, we came to a greater appreciation regarding the harmful consequences of missing or erroneous information (Redman, 2016), its contribution to misdiagnosis, weak decision-making and of course undesirable economic effects and clinician satisfaction (Schraa et al., 1982). Moreover, patients are often subjected to avoidable costly medical procedures, frequently instigating unnecessary pain and suffering

(Personal Injury Team Ireland, 2017). In tandem with this, the upshot of poor-quality information leading to misdiagnosis can result in a patient's ailment deteriorating and life-changing after-effects, substantial psychological suffering, mental issues, or death (Ibid). Additionally, our study shows that patients or carers feel less empowered and experience augmented stress levels as a result of being unable to remember their medical history.

As I explained in Chapter 2, it was only over the course of time that I really came to appreciate the impact of poor memory recall *within* the medical appointment and the negative experiences that CF patients/carers faced therein. However, the challenge that I then faced was how to best communicate this to others, particularly those within the IS field? Hence, in Paper 4 (Chapter 3) I presented an adapted People, Process, Technology, Data conceptual framework of the medical appointment view to facilitate the comprehension of the environment (Figure 3-1). This was appropriate as humans can often be constrained in their capabilities to comprehend or cognitively process complex informational structures or environments. Our model/abstraction of the medical appointment in Figure 3-1 facilities reaching a shared understanding and a means for discussion/examination of memory recall/information retrieval of a patients' medical history within the multifaceted setting of the medical appointment and the importance of same to diagnosis/decision-making. Later in Outputs 1, 2 and 3 we will exhibit other models that serve to augment our understanding and appreciation of the two key information phases of the medical appointment (the *elicitation* phase and the *elucidation phase*), albeit from a slightly different/deeper perspective.

4.2.2 Objective Two

Rationalise the research paradigm, methods, and techniques appropriate to the research objective.

As previously stated, our research is heavily influenced by our ontological viewpoint, which dictates our epistemological beliefs, rationalising our perception of the world, communicating "*our more or less dumb sense of what life honestly and deeply means"* James (1960, p.17), the design of our research, the choices we make and the actions we choose.

As I maintained in Chapter 1, I consider myself a pragmatist, but I have applied an interpretivist lens in order to attain my research aim. As a pragmatist my research method needed to be aligned with my desired practical outcomes, engendering real value to the CF community. On the other hand, using an interpretivist lens, I sought to understand CF patients/carers and doctors, and the activities *within* the two key information phases of the medical appointment. Here it became essential to understand these stakeholders within their real-world setting, multiple realities, and perspectives.

As seen in this study, I went to great lengths to understand the dynamics of the medical appointment and the impact that the check list (artefact) intervention was having on memory recall/informational retrieval, stress and empowerment. This may come as a surprise to many, as I am a CF patient myself living with the condition for over 48 years. However, as I stated before but wish to reiterate here once more, it is crucial to understand that even though one may have the same

illness as others (in my case CF), we are also individuals, different from others, travelling our own unique journey. Patients and indeed carers experience a disease and medical environments in diverse ways, influenced by a multitude of variables, such as culture, upbringing, experiences etc. We are not the same.

Hence, we need to put effort into comprehending individuals' "*lived experiences*", their thoughts, emotions, actions/behaviours, "*to count the humblest and most personal experiences"* (James, 1904, p.12). And so, empathy became a cornerstone of my research approach, *finding the echoes of another person in myself* – writer Mohsin Hamid. Moreover, I would argue that this human-centric approach was one of the critical success factors of the check list design.

As I mentioned previously, the success of any research hinges on the selection of an appropriate methodology, one that matches the personality and intended outcomes of the researcher. I believe it is crucial to choose a method that resonates with the researcher, in order to truly achieve success, akin (metaphorically speaking) to a lock and key. And so, Action Design Research (ADR) became my methodology of choice, owing to its suitability to the design and evaluation of artefacts that support human objectives (Simon, 1996). Papers 1, 4 and 5 outlined how I broadly followed an Action Design Research '*problem solving'* paradigm (Niehaves, 2007), which is considered apt in situations where research seeks 'utility' (March & Smith, 1995), or the design of artefacts within real world settings in order to generate impacts and the abstract knowledge (discussed later) required to address research questions. Moreover, it is appropriate when research aims to create artefacts that address so-called 'wicked problems' (Hevner et al., 2004).

4.2.3 Objective Three

Develop an artefact in the form of a check list that aids CF patients/carers memory recall *within* the medical appointment environment.

In Paper 5, I reflected on my ADR journey and *"Tragic Thursday"*, the day I halted my app idea intended to address the information needs of CF patients and carers, and decided that a change of approach/direction was required prior to the pursuance of any digital artefact. This was deemed necessary in order to avoid Type III errors, developing the wrong artefact/tool (Kaufmann & Sternberg, 2019). And so, as described in Paper 1 (Appendix A), I decided to engage in paper-based prototyping/pretotyping in order to understand the problem to be solved. Not only did the pretotype/artefact (in the form of a check list) aid my understanding of the problem on a deeper level, it also served (as we have seen earlier) as a serious aid to CF patient/carer memory recall *within* the medical appointment setting.

If truth be told, I was as surprised as anyone that this simple paper-based artefact had the impact that it did/does. In fact, one interesting observation is people's initial reaction to the check list (not including patients/clinicians/carers). I sometimes encounter rather subdued responses, which I can understand completely. To be honest, I would have been the very same when I started my ADR journey. Unfortunately, in today's technocentric world, it often takes a great deal to impress/excite people. Indeed, I would go so far as to say that this aspect of the present-day human character may indeed be contributing to some of the issues, I discussed in Chapter 2, on how problems are frequently approached, where we rush to solutions, before we have ever really understood a problem.

At first when one looks at the artefact in this study it may look too simple. It was designed to be so. The medical appointment environment is challenging enough for patients/carers without introducing anything that may complicate it further. This is not to say that change was not required, as we saw in Paper 1 (Appendix A) the use of the check list demanded/demands behavioural changes, be it doing *new things* (e.g. filling in certain sections of the check list *before* the appointment, acting somewhat like a rehearsal for the appointment, which in itself aids memory recall White et al., 1995), *doing things better* (e.g. asking the doctor more relevant questions to enable sections of the check list to be completed *during* the appointment) and *halting* certain behaviours (e.g. guessing/estimating in response to questions posed by the doctor *during* the *elicitation* phase, due to an inability to remember medical history information).

The check list/artefact in this project aids CF patients/carers memory recall, reduces stress and empowers patients/carers *within* the medical appointment environment. Moreover, the study confirms that simplicity (a critical aspect to my research endeavours) is linked to impact/s. Not surprising then that Leonardo da Vinci referred to simplicity as *"the ultimate sophistication"*. And so, as designers and innovators we should not confuse complexity with winning innovation. Often less is more, and having too many bells and whistles is a recipe for disaster. Perhaps then, we need to re-learn how we look at the world, to be more receptive, tempering knee-jerk considerations, looking beyond the horizon of what may at first glance seem obvious and too simple to be worthy of further consideration and celebration.

4.3 Research Contributions

Earlier in Chapter 1, we visited the contributions/impacts that this study has made to both practice and knowledge. Table 4-2 summarises these contributions, including theoretical context linking the primary findings to the existing body of knowledge. I will now visit both contribution types briefly in this final chapter of the thesis, starting with the contributions to practice.

Table 4-2 Study Contributions to Knowledge and Practice

Contributions				
Paper	**To Knowledge**	**Context**	**To Practice**	**Context**
1	Insights gained are an essential precursor to the creation of any effective digital solution	Insights on solutions are hugely important to solution success. In some cases, *"we may be too ready to re-use features of known existing designs, rather than to explore the problem and generate new design features" (Cross, 2007, p.104)*. Aiding our understanding of a problem greatly influences our selection of solutions (Kaufman & Sternberg, 2019) and helps avoid Type III errors, solving the wrong problem (Smith, 1989), resulting in situations where digital solutions don't live up to their potential (Huckman & Stern, 2018).	Reducing CF patients/carers stress levels within the medical appointment.	Reducing stress is crucial as stress effects our ability to remember and has significant associations on physical and mental health (Quinter et al., 2016; Kessels, 2003; Jansen, 2008; Safeer, 2005; Ley, 1979). As the very context of the medical appointment can induce stress for both patient and carers (making doctor-patient communication challenging) (Ong et al., 1995), ameliorating same is beneficial in and of itself.
			Improving CF patients/carers sense of empowerment within the medical appointment	Patients/carers reported an increase sense of in empowerment using the check list. This is important as patients/carers are known to engage in their illness more when they feel empowered to do so (Prigge et al., 2015). In addition, an increased sense of empowerment is known to improve the efficacy of treatments as it augments adherence to therapy regimes (ibid). Moreover, the World Health Organization has prioritised empowerment as a subject matter to be pursued globally (Delnoij et al., 2013).

Table 4-2 continued …

Contributions				
Paper	**To Knowledge**	**Context**	**To Practice**	**Context**
2 & 3	Reveals the prevalence of long-term information retrieval/memory recall concepts, patient/carer memory recall challenges, including the disease states in which patient information retrieval/memory recall research has been conducted over the past 43 years.	The main contribution is the insight into the various memory types (and frequencies of same) drawn upon by the patient/carer within the medical appointment i.e., episodic, autobiographical and prospective memory. Moreover, it highlights/explores the challenges (including frequencies of same) to memory recall reported in literature; emotional state where stress is reported to have significant effects on memory recall (Kessels, 2003), forgetting (viewed through Schacters (2001) The Seven Sins of Memory), resulting in data with a high probability of being in error, where dating is found to be based on inference, estimation and guesswork (Brown et al., 1986), and health literacy (Martin et al., 2014). Such insights are vital to the creation of solutions to aid memory recall/information retrieval within the medical appointment.	All stakeholders gain a greater understanding of the importance of long-term memory components and memory recall/ information retrieval challenges *within* the medical appointment.	Reports show that efforts to deal with memory recall issues (by clinicians) have shown to influence outcomes (Bartlett et al., 1984; Schillinger et al., 2003). Furthermore, doctors are described as poor at identifying their patients' health literacy levels (Seligman et al., 2005), and the impacts that same has on clinical outcomes (Bennett et al., 1998; Kalichman & Rompa, 2000; Schillinger et al., 2002; Dewalt et al., 2004). Given the importance of medical history accuracy to the diagnostic process, and to appointment outcomes, I hope that this study may result in the medical community rethinking their approach to the *elicitation* phase within the appointment, more especially since attempts to address memory recall issues by clinicians in the past have shown to influence outcomes (Bartlett et al., 1984; Schillinger et al., 2003). Regarding patients/carers, they gain an awareness of how much information they actually forget, and how quickly they can forget it (40–80% of medical information imparted by doctors is forgotten immediately - Kessels, 2003).

Table 4-2 continued …

Contributions				
Paper	**To Knowledge**	**Context**	**To Practice**	**Context**
2 & 3	Conceptual model of information retrieval/memory recall *within* the *elicitation* phase of the medical appointment	Research on the *elicitation* phase of the medical appointment has received far less attention than the *elucidation* phase (Cohen 1995). 46% of the medical appointment consists of this stage, which is vital to the appointments' success, as 99 percent of patient day to day activities can occur in non-clinical environments (Martin et al., 2014). The patient's medical history equips the doctor with between 60 and 80 percent of the data required to facilitate a diagnosis (Hampton et al., 1975; Sandler, 1980; Kassirer, 1983). Hence, an increased understanding vis-à-vis this phase is very beneficial to researchers/stakeholders.	The model serves to explain the intricacies/ workings of the medical appointment to clinicians, patients and carers etc, acting as a mental model if you will, facilitating a shared understanding of this complex environment.	Patients/carers gain a realisation of the various types of memory they use *within* the appointment, the challenges to memory recall therein, and most importantly, the affects that poor memory recall can have on the medical appointment outcomes. They also come to appreciate the effects their emotional reactions Schwabe & Wolf (2010) and biases (overconfidence or projection bias (Loewenstein, O 'Donoghue and Rabin 2003)) can have on the retrieval of information. Of course, the knowledge that transience can sometimes be overcome with cues and hints provided *during* a conversation (Tulving & Pearlstone, 1966; Koutstaal & Schacter, 1997) may also result in behavioural changes *within* the *elicitation* phase of the appointment.

Table 4-2 continued …

Contributions				
Paper	**To Knowledge**	**Context**	**To Practice**	**Context**
4	Presents a representative set of design principles for the design of a check list for use by patients/ carers to aid memory recall. The most novel of which is the unpacking of declarative memory into its components, where the check list design actually maps to "*aid*" the memory type drawn upon by the patient/carer *within* the medical appointment.	Table 3-4 & Table 3-5 outlines the DPS contributions to knowledge including theoretical context.	Improves CF patients/carers ability to recall key clinical data *within* and *after* the medical appointment	*Within the appointment* The Check List acts as a memory recall aid apropos the patients' medical history, including current wellbeing, present treatments/medication and so on. In the region of 46% of the medical appointment consists of this stage, and is vital to the appointments' success (Bickley, 2013; Martin et al., 2014). *After the appointment* Reports confirm that memory recall /information retrieval in this phase of the medical appointment have direct impacts on adherence and other self-managing activities (McPherson et al., 2008). Improvements in patient/carer memory recall also result in better health outcomes and patient satisfaction (Schraa et al., 1982).

Table 4-2 continued …

Contributions				
Paper	**To Knowledge**	**Context**	**To Practice**	**Context**
4			The check list facilitates specific CF related data recollection *before* and *during* a medical appointment.	*Before the appointment* Rehearsal for an appointment aids memory recall (White et al., 1995). The check list also acts as a cue/prompt - tactics that aid memory recall /information retrieval such as cues, hints, or indeed testing patients recall, have all been found to aid memory recall /information retrieval (Tulving & Pearlstone, 1966; Koutstaal & Schacter, 1997). *During the appointment* The use of check lists in health care is now widespread as they have proven to be so beneficial in preventing memory failures (Stock et al., 2015). In complex environments, not only do check lists help, they are required for successful memory recall (Gawande, 2010).

Table 4-2 continued …

Contributions				
Paper	**To Knowledge**	**Context**	**To Practice**	**Context**
5	Visualisation/ model of reflection within the context of the ADR project, in tandem with the tacit knowledge of "*problem formulation*" within an ADR journey.	According to 1998 Berthon et al. (1998), "*problem formulation*" is the least researched of problem-solving activities. Mitroff et al. (1979) maintain that problem forming and defining are as critical, if not more so, than problem solving. Regarding ADR, Mullarkey & Hevner (2018) recount the challenges they had regarding the "*problem formulation"* stage. Building on this we propose the levels of inquiry one needs to go to in order to more fully understand a problem.	The designed check list is new discursive template that facilitates a new patient led approach to tackling the problem of memory recall *within* the medical appointments.	Hitherto, I have encountered no such memory recall tool for use by patients/carers within the medical appointment. Moreover, I have not come across any patient led research projects in this area.

4.3.1 Contributions to Practice

When I set out on this journey, I set myself the challenge of addressing the problem of memory recall for CF patients/carers *within* the medical appointment. As I sit here looking out the window on 9th June 2020, just after my first virtual medical appointment due to Coronavirus COVID-19 (SARS-CoV-2), I ask myself "*have you succeeded?*" Well yes and no. The yes, I will discuss here, the no, I will discuss later in this chapter, in the limitations of the study, and future research. So, with regards to practice what has been achieved? From a practical perspective, as the check list has been designed by CF patients/carers and clinicians for CF patients/carers this facilitates real specific CF-related data recollection and capture *within* (*before* and *after*) a medical appointment. While Table 4-2 summarises the contributions to date, I feel these contributions are deserving of further comment/consideration at this juncture.

The artefact results in a number of important key benefits: first, facilitating the straightforward capture of key clinical data *before* and *within* a medical appointment, in tandem with, the recall of such medical history (critical for diagnosis) as required, where 81% of participants reported an increase in their ability to remember their medical history and what had happened at their respective appointments. Second, reducing stress (which negatively affects memory recall), where all 18 participants said that it had decreased their stress levels, with 72% of them rating this at a 4 or greater on a Likert scale of 1-5. Third, the artefact increases CF patients/carers sense of empowerment (critical to patient engagement), where 15 out of our 18 participants gave a 4 or 5 when asked to rate the check list on a

Likert scale of 1-5. Mika et al. (2007) contend that the very act of publicising questions empowers patients to ask questions, and also aids them in prioritising the questions of greatest consequence to them.

As one would expect in a project which took a human-centred design approach, it was important to move beyond viewing these impacts on a macro level, to a more micro scale (Table 1-1 in Chapter 1), assisting in the true appreciation of the impacts of the check list on the individual, on the human beings in the story, real CF patients/carers, living with the illness and the problem of memory recall/information retrieval *within* their medical appointments. Observations such as, *"For me the check list works so well as I now rely less on my own faulty memory. To be honest, having used it now for a few months I would be lost without"*, or *"With the check list for the first time I could really hear what the doctor was saying to me"*, provokes empathy and a deeper understanding of the real value that the check list bestows to CF patients and carers.

Perhaps it is not altogether surprising then, that in 2019 the artefact/check list booklet was distributed to all CF patients/carers (1,300 CF homes) within Ireland by Cystic Fibrosis Ireland (my Irish Research Council Enterprise partner). The reaction/appreciation by CF patients/carers we saw encapsulated in Table 1-2 (Chapter 1). However, one poignant comment is worth repeating, made by a CF mother regarding her 7-year-old CF son, "*though it's just a book now to him, in a few years he'll know how great it is as well*".

Fourth, the artefact augments all stakeholders understanding of data capture and memory recall/information retrieval *within* a medical appointment and the

importance of same. Patients/carers gain an increased awareness of how much information they actually forget, data that necessitates capture and recall. Moreover, they come to appreciate how quickly they can forget, together with a consciousness of the various challenges that exist, which directly and/or indirectly, affects their capability to remember information accurately, impacting on the outcomes of their medical appointments. Additionally, patients/carers come to realise the new behaviours that are required whilst using the check list to ameliorate the problem of poor memory recall/informational retrieval *within* the medical appointment, such as doing new things (e.g. completing particular parts of the check list prior to an appointment (which in itself aids memory recall)), doing things better (preparing questions and remembering to ask them) and halting certain behaviours (e.g. guesstimating/haphazard responses due to an inability to remember key medical history information).

Fifth, the clinician gains a more in-depth understanding/appreciation of the importance of long-term memory components and memory recall/information retrieval challenges *within* the medical appointment. McKinstry et al. (2011) report that doctors rarely use approaches to try to ameliorate the poor information retrieved by the patient/carer *within* the *elicitation* phase of medical appointment, despite the effect that such poor data has on their ability to make an accurate diagnosis. As we saw in Paper 1, the Paediatric team at a local hospital in Cork were initially cautious of the check list, however the Paediatric unit are now actively providing carers with their child's medical data to help them record their medical data on their check lists. Hence, the check list appears to/may change the behaviours of doctors after they become aware of the benefits of same.

The clinical reaction to the check list over the course of the study has been overwhelming positive (Table 1-3 in Chapter 1), summed up by the comment from one clinician, *"I think the check list is a great idea and should really make a difference to medical appointments outcomes"*. Doctors live with the reality of having to formulate a diagnosis using very poor-quality medical histories on a daily basis. Hence, solutions that improve the quality of information imparted by the patient/carer, in tandem with augmented engagement and better adherence to medical regimes are always most welcome.

As previously mentioned, the endorsements from clinicians led to several invites to present at clinician-only conferences, assemblies where invites are only extended to impactful/novel medical topics of interest to the CF medical community. As mentioned, these invitations led to opportunities to send the check list booklet to eight other countries (Figure 1-5, Chapter 1). In February 2020 hospitals within the NHS such as the Royal London Children's Hospital, in London, and Cambridge University Hospital, in Cambridge, started the distribution of the check list to CF carers.

Finally, the check list artefact is a new (in terms of structure, design and usage context) discursive template that enables a contemporary patient-led move toward confronting the problem of memory recall/information retrieval with the medical appointment. This is unique as hitherto, no such tool existed for CF patients/carers to assist them in the act of remembering *within* a clinical encounter. Moreover, the artefact aids CF clinical research as it contributes to our understanding of how a

check list designed to aid memory recall enhances a CF patients/ carer's well-being (in terms of stress and empowerment), as the evaluations conducted have revealed.

Thus far, research on memory recall *within* the medical appointment appears to have been conducted primarily by clinicians, and hitherto, I have not encountered any research done by an actual CF patient on the subject (or any other patient for that matter), who is essentially living with the difficulty identified. Therefore, the research underlines the enriching insights and contributions to knowledge that patients can make to health innovation and research. This supports von Hippel's (2013) contention that ideas for novel or improved solutions are often best brought about by those users who seek solutions to serve their own needs.

4.3.2 Contributions to Knowledge

The artefact in this research took the form of a check list, simple, and yet genuinely effective. Initially, the check list was only meant to be a pretotype (a paper-based prototype, bought about by the events of "*Tragic Thursday"* - Chapter 2/Paper 5), a precursor to gauge initial user appeal and behaviours *within* the context of the doctor-patient/carer encounter, prior to the creation of any digital solution. For me it became way more than that; it also allowed me to gain a comprehensive understanding of the memory recall/information retrieval experience/s that patients/carers lived through. Moreover, it facilitated insights regarding their use of the check list *within* real-world medical appointments, cheaply and yet really effectively. For instance, identifying what was missing (completeness – of those "*killer items*"), what functioned well and what didn't (usability). These learnings were invaluable in my quest to improving/refining the artefact, and will hopefully

serve as essential antecedents to the design/creation of any future digital solution/s, to aid memory recall for CF patients/carers in alternative situations, for example *outside*/*between* medical appointments (considered shortly). Indeed, I believe that the benefits of this check list/pretotype as a forerunner to a digital intervention should not be understated. In fact, I would advocate the use of such insightful precursors prior to the creation of any digital intervention (where a human is the intended user). This is not to say that the check list/pretotype in this study was/is a catch all, ticking every box vis-à-vis user needs/wants. It has, of course, limitations (deliberated upon later).

The literature review (Paper 2 - Appendix B and Paper 3 - Appendix C) augments our understanding of memory recall and its significance *within* the medical appointment, revealing the prevalence of long-term declarative memory concepts within the literature over the past 43 years, exposing the need for an increased understanding of Autobiographical memory and Prospective memory *within* the medical appointment, and information retrieval/memory recall research in various human systems/disease states.

Additionally, the review exposes the challenges of memory recall/information retrieval reported within the literature, including; forgetting, health literacy and emotional state. The benefits of understanding same are as follows; doctors gain a more comprehensive understanding of the memory recall/information retrieval challenges that must be overcome *within* the medical appointment, in order to improve data accuracy and diagnosis. The medical community also comes to comprehend that doctors may need assistance, training (including awareness) and

time to recognise these memory recall challenges more effectively. For instance, training on techniques or strategies that can aid memory recall/information retrieval such as the use of patient/carer check lists with the medical appointment. Furthermore, the enquiry highlights the future research opportunities that exist (visited later).

What is quite striking about the review is the scarcity of IS publications in information retrieval/memory recall *within* the medical appointment (which is essentially a data retrieval/data quality issue, albeit *within* a unique environment. While some within the IS community may take the view that the research and its findings are only of interest to a medical audience, and struggle to see its place within IS. I would contend that the opportunities for IS research are rich and indeed worthy of consideration.

I substantiated same by way of a conceptualisation of the *elicitation* phase of the medical appointment first presented in Paper 2 (Appendix B), and advanced in Paper 3 (Appendix C). The current model Figure 4-1 shows models from both papers (Figure B-6 in Appendix B and Figure C-3 in Appendix C) combined into one, and endeavours to depict the bilateral dialogue between the doctor and the patient/carer, through the lens of memory recall/information retrieval, the impact that memory recall has on the quality of data imparted by the patient/carer, which is communicated back to the doctor, the importance of which, we have already outlined as a critical input into the diagnostic process undertaken by the doctor.

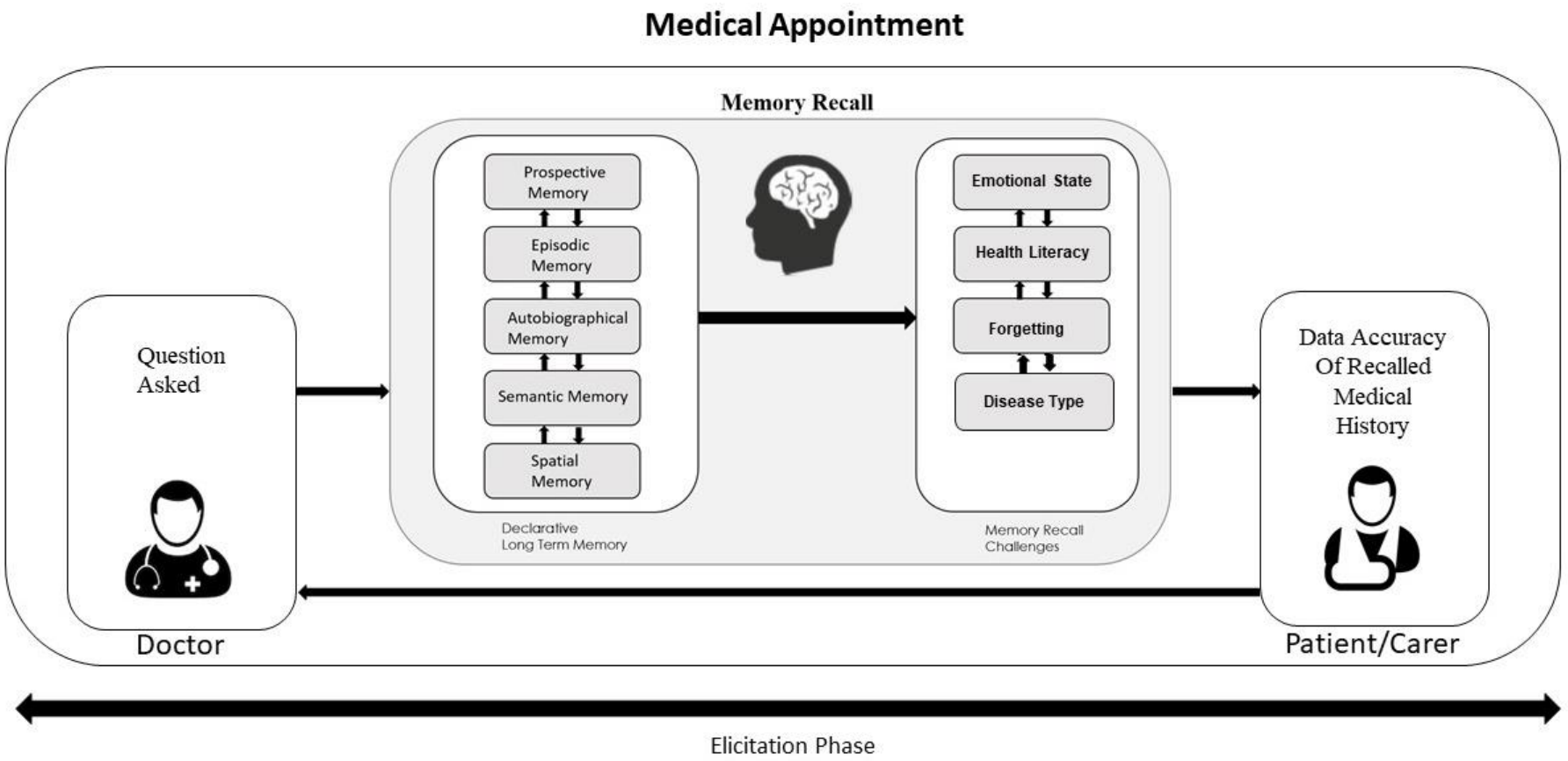


Figure 4-1 Conceptual model of Elicitation Phase of the medical appointment (advanced -combined)

The model supports the idea of the various declarative long-term memory (LTM) components employed by the patient/carer following inquiry by the doctor, regarding the patients' medical history in the form of questions.

Additionally, the amalgamated memory recall/information retrieval challenges have been pulled together from both literature review papers (giving a set of four significant impediments to the memory recall process) and placed within the memory recall process. As explained in Paper 4 (Chapter 3) and Paper 5 (where I reflected on my ADR journey -Chapter 2), Paper 2 (Appendix B) and Paper 3 (Appendix C), and the model above that came to light therein, were major contributors to my understanding and appreciation of why the check list worked as well as it did *within* the medical appointments of CF patients/carers. Put simply, I had moved beyond information needs, and memory recall at its most basic level, to a far deeper/richer appreciation. Now I could see how the various long-term declarative memory components mapped onto the check list serving as a tool capturing a moment in time, and where the booklet became an autobiographical repository of medical discourse, available and easy to use.

However, as the model intimates (observe the single black arrow between the declarative long-term memory components and memory recall/information retrieval challenges), there is still much to learn regarding the challenges identified, and the connections between the components of declarative long-term memory. Therefore, the model depicts the advancement of knowledge regarding memory recall/information retrieval *within* the medical appointment, and also raises a number of questions vis-à-vis the relationships that exist between declarative LTM (and its components) and the memory recall/information retrieval challenges that

exist *within* this clinical encounter between doctor and patient/carer. The model uncovers a number of possible directions for future research, especially for those in IS, which we will discuss later in this chapter under *future directions for research*.

Paper 4 (Chapter 3) takes a *People, Process, Technology, Data* lens and presents a representative set of emergent design principles for the design of a check list for use by patients/carers to aid memory recall. The most novel of which is the unpacking of declarative memory into its components, where the check list design actually maps to *"aid*" the memory type drawn upon by the patient/carer *within* the medical appointment. As revealed in Paper 4, this design principle emerged via inductive reasoning following a review of extant literature (in long-term declarative memory) and analysis of medical appointment narratives, revealing the "*why"* behind the check list success.

In spite of this, this cognitive design principle needs further consideration, exploration and dissemination (see future research). Designing a check list that is adapted to the needs of patients *within* the medical appointment is more complex than it seems. While the ten key DPs that emerged in this study informed the creation of a check list for CF patients/carers, they may also be valid in the creation of other innovations aimed to aid memory recall for other illnesses, augmenting both the quality of data captured (for use *after* the medical appointment) and imparted, improving diagnostic decision-making purposes and appointment/patient outcomes.

The artefact/pretotype in this research took the form of a check list, with a set of 10 design principles, which will hopefully translate into a digital artefact, aiding

memory recall for CF patients/carers in alternative situations, for example *outside*/*between* medical appointments (considered shortly). Additionally, I have demonstrated how beneficial pretotyping is as a means to gauge initial user appeal and behaviours prior to the creation of any digital innovations, *within* the context of the doctor-patient/carer encounter. Therefore, I would encourage the inclusion of pretotyping in the initial iterations of many ADR projects, if not to advance an artefact/solution, to advance one's appreciation of a problem.

Unfortunately, that a small amount is appreciated vis-à-vis how problems are formulated in ADR seems as true today as it was six decades ago. And so, in my final paper, Paper 5 (Chapter 2), my methodology paper, I used Driscoll's (2001) Model of Reflection (and a series of four vignettes) to rationalise/examine the part of Action Design Research that I struggled with the most, that of "*problem formulation*". Why? I suppose I felt I had something to "*get off my chest*" so to speak regarding this aspect of ADR. Moreover, having played a dual role, as both a patient and researcher in my ADR research, I felt I had something to offer, something a little different, particular tacit knowledge, that just may assist others in avoiding the mistakes I made. This reflection also resulted in a visualisation of my ADR project (Figure 4-2). The model depicts the various stages of ADR, but with a focus and appropriate consideration as regards *"problem formulation"*. Buttressing the need for a problem to be revisited again and again, while also portraying the depths of exploration required to thoroughly understand a problem, where several possible ways of examining a problem have been considered, explored, and understood. An endpoint, where through grit and determination successful end results are reached.

The model and the tacit knowledge arising out of the four vignettes serve as knowledge contributions in their own right. Furthermore, they also are a wonderful way for me to think back, reflect, and gain a deep appreciation for the road that I have travelled. In fact, I would go so far as to say that writing Paper 5 was therapeutic.

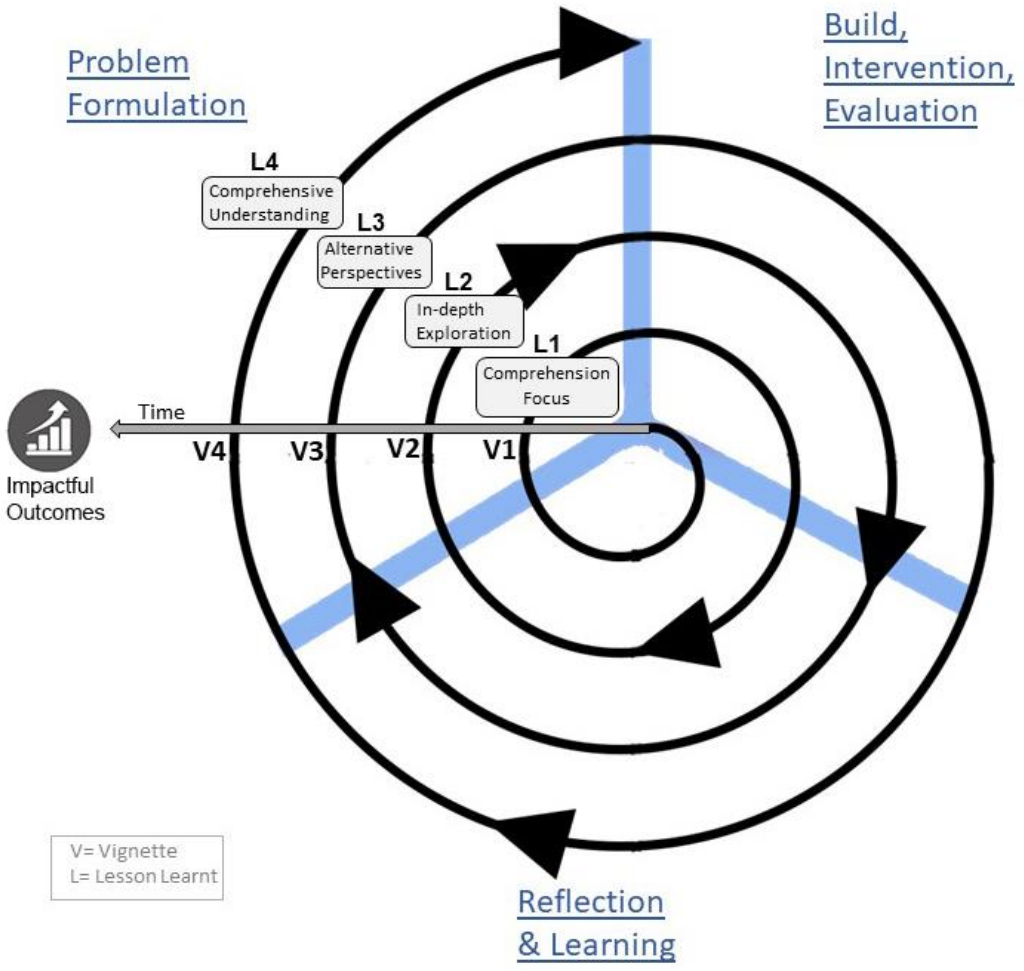


Figure 4-2 Visualisation of Reflection Within the Context of the ADR Project

Knowledge contributions come in many different forms and flavours, many of which I believe are lost due to the sanitisation of research. I frequently ask/ed myself why? Is it the need to portray a sense of perfection or virtuosity amongst our peers? I feel we are missing the secret sauce, those stories screaming to be told. The

tales of struggle, resilience, grit, and determination. I believe and indeed demonstrate in Paper 5, why these narratives need to be told. Not only do they embrace our humanity, they enrich our research, begetting a sense of realism to ADR, serving as knowledge contributions in their own right. Capturing that tacit knowledge that is all too often lost, left behind, left to sink into the depths of "*Davy Jones' locker"*. Moreover, it facilitates a sense of the researcher behind the research. This is why I re-counted my story as I did, I wanted you the reader to identify with the human behind the research, to hear the real un-sanitised/raw story of my ADR journey

Nevertheless, Paper 5 would never have come together the way it did had I not kept a record of my PhD journey through a series of diaries. This is something I would encourages every PhD student/researcher to do. Why? I feel that it facilitates the capture of a myriad of valuable information such as: progression of thoughts/mental models, the *why* behind decisions made, or indeed not made. Aiding the capture of moments, instants of triumph, adversity, and enlightenment. Put simply, a temporal chronicle of insight, which can be used again and again to deliver silent knowledge, learnings that are so often lost or forgotten. Perhaps we are in such a rush to get to the next milestone or phase of a project, that we fail to see the actual riches within our own thoughts, decisions and experiences. This I feel is such a shame, and such a wasted opportunity for learning and knowledge generation, and so I felt it important to mention here.

4.4 Limitations of Study

Despite the best efforts of scholars, research studies will often be constrained by one or more factors, such as time and resources. Many studies suffer from flaws which can affect the quality, the validity, or the robustness of the knowledge claims of the study. This study, like all others, was restricted in some respects. The objective of this section is, therefore, to address the question of "*what are the limitations of the study that affect the validity and generalisability of its knowledge claims"*?

This study has a number of limitations. Firstly, the size of evaluation groups is limited. Therefore, one may argue that our qualitative results at best indicate a strong trend but are not statistically meaningful. In counter to this, the check list booklet has been evaluated/considered by the CFI and subsequently distributed by them to 1,300 homes around Ireland, as a memory recall aid for CF patients/carers. The response from the CF community has been incredible, with requests to review the booklet from eight other countries, where the booklet is now been distributed by NHS hospitals, such as the Royal London Children's Hospital, in London. In tandem with this, there have been many invites to present at esteemed clinical conferences, where the response from doctors and other clinicians has been extremely positive.

Bias can always be an issue in research endeavours, hence I/we needed to be mindful of the bias in our approach, for instance how would we/I deal with observer bias? To this end, interviews were conducted with reliable objective data collection tools in the form of externally vetted questionnaires which were designed not to

lead the participant but to facilitate the capture of insights. Moreover, as the lead researcher, a CF patient myself, I was aware of the bias that I was bringing to the study. As mentioned previously, I came to appreciate this very quickly, where even though I share an illness with the participants, their journey and stories were quite different to mine, and thus, needed to be heard and understood through an open mind, via meticulous empathetic listening.

The presence of a Hawthorne effect is also worthy of consideration, that is to say the evaluation of the check list was influenced by the reality that the participants realised that they would be interviewed after each iteration, and consequently may have been more inclined to use the check list. On the other hand, the longitudinal utilisation of the check list by CF patients and carers would offset this.

My literature review (Paper 2 – Appendix B and Paper 3 – Appendix C) uncovered three key limitations, firstly, the exploration was only performed on peer reviewed academic journals, excluding publications in books and websites articles, which may have enhanced the review further. Also, as already commented on, there are other contexts involving patient recall excluded from the search criteria (*within* the medical appointment), that may enhance our comprehension of patient/carer memory recall/information retrieval. This may well be true, only future research will reveal this. Secondly, it could be reasoned that the search criteria are too restrictive, and that some seminal papers have been overlooked. In counterpoint to this, I have examined 39 databases, traversing disciplines to achieve as complete a vista of the literature as possible. Thirdly, there is an absence of analysis on the topic of solutions addressing the challenges of memory recall/information retrieval

within the medical appointment setting. Responding to this an initial analysis has been done (Appendix P), however the examination needs to be completed, it will be important to analyse these tools and to consider their utility, usability, robustness and the opportunity to identify any analogs/antilogs that they may present. And so, this presents an opportunity for further research.

Of course, the artefact itself has many limitations, and many questions still remain unanswered, such as, how can we best harvest insights from all the data captured in the check list? It will also be important to attend to the concerns raised by patients uncomfortable completing the "*emotional state*" section of the check list. And so, where should a check lists booklet/s be stored, in order to address the security and privacy of users? Many questions still remain unanswered, bestowing numerous prospects for research into the future. And so, let us consider the future research opportunities.

4.5 Future Work

In addition to the significant contributions made to academia and practice by this study, the current research also provides some important directions for future research and practice. The objective of this section is, therefore, to outline the directions that research and practice may take in the future. As one might expect, a considerable overlap exists between both.

4.5.1 Future Directions for Research

The conceptualised model of the *elicitation* phase in Paper 2 (Appendix B) and Paper 3 (Appendix C) reveals a number of conceivable routes for future research,

as many questions remain to be answered, for example, do we know a sufficient amount about the relationships that exist amongst the declarative LTM components in the context of the medical appointment encounter? Moreover, the review exposed the need for an increased understanding of Autobiographical memory and Prospective memory *within* the medical appointment. It will be important for us to hypothesise the relationships that exist between such declarative LTM components and the information retrieval/memory recall challenges that exist for *within* the medical appointment. Indeed, Paper 2 (following classification) identified 38 empirical studies and 11 conceptual (10 of which were literature review papers). This imbalance may well indicate the need for an increase in more conceptual methods and the opportunity for theory building.

Like all human environments, the medical appointment is changing/evolving. For example, day by day medical appointments are moving online due to a number of factors, for instance, a growing shortage of doctors, challenging geographical locations (access to healthcare) and the evolving COVID-19 pandemic, all leading to the rapid adoption of telemedicine technologies. How then might we best adjust to this new dynamic? Do we understand the workings of the recall/communicative process *within* the medical appointment sufficiently, to be able to create adaptive innovative solutions to improve memory recall *within* the transforming landscape of the medical appointment? Furthermore, how will/should we address the privacy concerns of users, so that they will be more comfortable using such innovations? Indeed, one could well ask does our research have a contribution/s to make to other challenging environments, settings where individuals engage in bidirectional

communication, where information is elicited from memory, and then utilised in critical decision-making processes?

As discussed earlier, in Paper 3 (Appendix C) there is also a need for an augmented in-depth understanding of the challenges to memory recall: forgetting, health literacy, emotional states and the various disease states (Paper 2 Appendix B) besides respiratory, that may affect memory. What other illnesses can affect remembering amongst patients? Also, the study highlights three other areas for future enquiry; that of patient/carer memory recall/information retrieval *before*, *after* and *between* medical appointments. Evoking many questions, for instance, how might we best collect data in these domains? For example, the tracking of symptoms occurring *between* the medical appointment? This raises the question as to how we may gain insights (discussed more in our next section) from all the data collected in our booklet? Thus, a future direction may include the digitisation of the check list (in some form), to investigate/validate the possibility of using same to seize such valuable (yet frequently uncaptured) data.

Diagnosis is a decision-making process, and whilst we have touched upon same in this research, I feel more is yet to be done regarding data quality and the decision-making process *within* this environment. Not only regarding the doctor and diagnosis, but also regarding the patient/carer and the decisions they endeavour to make, whilst often under extreme duress.

There is no doubt this study has brought to light a broad range of research opportunities, areas to be further considered and dissected, increasing our comprehension of this complex environment and the environs beyond.

4.5.2 Future Directions for Practice

I am sitting here at 3:59pm, on 11 June 2020, contemplating my PhD. I am approaching the end of my PhD passage, and yet I feel I am only at the start of the journey. Why? I suppose as a researcher I have accomplished a great deal in this short space of time; there's no doubt the check list is a success story and extremely impactful. However, as a patient living with this disease, I also see many gaps, issues that need to be addressed.

Let me explain. As a patient I also want/need to capture data beyond the confines of the medical appointment. I am also trying to manage my condition on a daily basis, 99% of which happens *outside* the appointment. While the check list works really well *within* the medical appointment, the patient/carer still has a number of unmet needs. Necessities that encompass, yet go beyond *within* the medical appointment, setting in this study. For instance, remembering to take medications/treatments throughout the day/week, the need to capture pertinent health related events, to deliver a more comprehensive picture of the patient, as they go about their life. Providing a holistic digital account of the patient/s, this accumulated data would furnish key stakeholders (doctors, researchers, patients, and carers) with insights on both the patient as an individual, and on patients as a collective (also extremely valuable to the pharmaceutical industry).

Only then may we advance our understanding of the individual patient, and patients as a group/s. For example, gathering insights on those sharing common genomes, treatments, etcetera. Thus, the data in the current check list needs to be analysed and be capable of analysis. Additionally, the scope of the data we need to consider

must be widened, in order to give a more complete picture of the patient/s. Consider wearables, such as fitness trackers, for example the Apple/Fitbit watches, and the information gathered by same. Of course, we must also be able to integrate (avoiding data silos) and back-up all this data, together with securing and addressing privacy (mentioned previously) and other data governance (including ethical) issues.

So, is the future digital? Does this mean the digitisation of the check list into a digital form? The path ahead seems to point in that direction, but we must not forget that digital artefacts can and often have significant negative impacts on the communication between the doctor and patient/carer (i.e., the use of electronic medical record systems in medical appointments). Thus, perhaps the future is a digital solution that addresses the above issues and yet advances/complements the current paper-based check list? Many questions remain. I have no doubt that many challenges lie ahead in endeavouring to answer the questions/issues raised herein, not least the progression to digital, in order to gain valuable insights, whilst still avoiding any interreference in the doctor patient/carer dialogue, vital *within* this vastly complex medical appointment setting.

4.6 Concluding Remarks

"*Memory for medical history, like other forms of autobiographical memory, is likely to be flawed, incomplete and erroneous*" (Cohen et al., 1995, p.273). Unfortunately, despite the patient's medical history long being recognised as being a critical input to the diagnostic process, the development/implementation of

solutions and practices to facilitate better memory recall have thus far been inadequate.

The contributions that this study makes to academia and practice exhibit a novel means of addressing/aiding memory recall with the medical appointment by way of: (1) a check list artefact or discursive template that enables a CF patient/carer to tackle the issue of memory recall/information retrieval *within* the medical appointment; (2) it contributes to our understanding of how a check list designed to aid memory recall enhances a CF patients/carer's well-being (in terms of stress and empowerment); (3) the check list is unique, in that hitherto, no such tool existed for CF patients/carers. And so, perhaps it comes as no surprise that the check list was distributed to 1,300 CF homes within Ireland, and has since travelled to eight other countries for review/use, most recently, leading to the distribution by hospitals within the NHS; (4) the research highlights the contributions to knowledge that patients can make to health innovation and research; (5) an increased understanding of memory recall *within* the *elicitation* phase of the medical appointment, and the challenges therein, including a model depicting same; (6) a set of 10 emergent design principles for the design of a check list to aid memory recall *within* the medical appointment, the most original of which is the dissection of long-term declarative memory into its components, where the artefact essentially maps to "*facilitate"* the memory type drawn upon by the patient/carer *within* the medical appointment; and (7) an abstraction of ADR, with a particular focus on *problem formulation* and the iterative depths of exploration required in order to understand a problem, and achieve successful outcomes. What unites each of these elements is the rigorous application of the ADR methodology, in tandem with a burning desire

and determination to deliver real impact. In this way the study has recast the concept of patient led innovation, which will hopefully serve to provoke others who aspire to make a difference.

I miss my dear sister, and I believe I have gone some way to honour her memory, by doing something that I know has brought a warm smile to her face. Thank you for listening to my story.

References

Ackermann S., Ghanim L., Heierle A., Hertwig R., Langewitz W., Mata R. & Bingisser R. (2016) Information structuring improves recall of emergency discharge information: a randomized clinical trial, Psychology, *Health & Medicine*, 22:6, 646-662.

Arriaga, A., Bader M., Wong J., Lipsitz S., Berry W., Ziewacz J., Hepner D., Boorman D., Pozner C., Smink D., Gawande A., (2013). *N Engl J Med* 2013; 368:246-253 January 17.

Baker, D. W., Parker, R. M., Williams, M. V., Pitkin, K., Parikh, N. S., Coates, W., & Imara, M. (1996). Th e health care experience of patients with low literacy. *Archives of Family Medicine*, 5 (6), 329–334.

Barrett, E. (2019) Don't Just Do Your Job, Designers. Do It Ethically. https://fortune.com/2019/03/15/design-ethics/

Bickley L, (2013) *Bates Guide to Physical Examination and History Taking*. 11th Edition. Published by Wolter Kluwer `Lippincott Williams & Wilkins.

Beauchamp T, Childress J (2001) *Principles of Biomedical Ethics*. 5th edn. Oxford University Press, Oxford.

Brown, N.R., Shevell, S.K. and Rips, L.J. (1986). *Public memories and their personal context.* In D.C. Rubin (ed). Autobiographical memory. Cambridge University Press.

Bundesen, Claus, Habekost, Thomas, Kyllingsbæk, Søren. (2005). A neural theory of visual attention: bridging cognition and neurophysiology. *Psychological Review*, Vol 112(2), 291-328.

Burns N, Grove SK (2005) *The Practice of Nursing Research. Conduct, Critique and Utilization*. 5th edn. WB Saunders, Philadelphia.

Cambridge Dictionary (2020) *Veracity*, https://dictionary.cambridge.org/dictionary/english/veracity

Chatterjee, S., Sarker, S., & Fuller, M. (2009). Ethical information systems development: A Baumanian postmodernist perspective. *Journal of the Association for Information Systems*, 10(11), 3.

Cohen, Gillian, and Rosalind Java. (1995) "Memory for Medical History: Accuracy of Recall." *Applied Cognitive Psychology* 9 (4): 273–88.

Collins. (2019) *Collins English Dictionary*. Glasgow: Harper Collins.

Conway, M. A. (1996). *Autobiographical memory*. In E. L. Bjork & R. A. Bjork (Eds.), Memory. San Diego, CA: Academic Press.

Coulter, A., & Ellins, J. (2007). Eff ectiveness of strategies for informing, educating, and involving patients. *British Medical Journal*, 335, 24–27.

Cramer, J. A (1991). *Identifying and improving compliance patterns*. In J. A. S. Cramer B. (Ed.), Patient compliance in medical practice and clinical trials (pp. 387–392). New York: Raven Press.

Cutler, RL, Fernandez- Llimos F, Frommer M, Benrimoj, C., Garcia-Cardenas, V. (2018) Economic impact of medication non-adherence by disease groups: a systematic review. *BMJ Open*;8: e016982.

Davis, T. C., Williams, M. V., Marin, E., Parker, R. M. and Glass, J. (2002), Health Literacy and Cancer Communication. CA: *A Cancer Journal for Clinicians*, 52: 134-149.

Davison, R. M. (2000). Professional ethics in information systems: A personal perspective. *Communications of the Association for Information Systems*, 3(1), 8.

Davison, R. M., Kock, N., Loch, K. D., & Clarke, R. (2001). Research ethics in information systems: would a code of practice help? *Communications of the Association for Information Systems*, 7(1), 4.

Delnoij, D., & Hafner, V. (2013). Exploring patient participation in reducing health care related safety risks. *World Health Organization*.

Doak, C. C., Doak, L. G., Friedell, G. H., & Meade, C. D. (1998). Improving comprehension for cancer patients with low literacy skills: Strategies for clinicians. CA: *A Cancer Journal for Clinicians*, 48 (3), 151–162.

Doak, C. C., Doak, L. G., & Root, J. (1996). *Teaching patients with low literacy skills* (2nd ed.). Philadelphia: J. B. Lippincott.

Driscoll, J., The, B. (2001). The potential of reflective practice to develop individual orthopaedic nurse practitioners and their practice, *Journal of Orthopaedic Nursing*, Volume 5, Issue 2, Pages 95-103.

Duckworth A., (2019) Self-Reports Spur Self-Reflection. *MIT Sloan Mgt. Review*. 60 (3):14-16.

European Commission (2013). *Ethics for researchers: Facilitating Research Excellence in FP7*. Retrieved from http://cordis.europa.eu/fp7/ethics_en.html.

Eysenck, MW. (2009) *Fundamental of psychology*. London (UK): Psychology Press.

Farley FH, Grant AP. (1976) Arousal and cognition: Memory for color versus black and white multimedia presentation. *J Psychol*. 94(1):147–150.

Federal Aviation Administration, (2016) *Handbook*. https://www.faa.gov/regulations_policies/handbooks_manuals/aviation/phak/media/pilot_handbook.pdf

Ferdi Van Heerden, *"Foreword," in Data Flow: Visualizing Information in Graphic Design*, ed. Robert Klanten et al. (Berlin: Gestalten, 2006), 8

Friedman, B., Kahn, P. H., & Borning, A. (2008). *Value sensitive design and information systems.* The handbook of information and computer ethics, 69-101.

Finney, S. et al., (2007) ERP implementation: a compilation and analysis of critical success factors, *Business Process Management Journal*, Vol. 13 Issue: 3, pp.329-347.

Gawande, A. (2010). *The checklist manifesto: How to get things right*. New York: Metropolitan Books.

Giardina TD, Menon S, Parrish DE, Sittig DF, Singh H. (2014) Patient access to medical records and healthcare outcomes: a systematic review. *J Am. Med Inform Assoc*. 21(4):737–41.

Gillespie, R., Florin, D., & Gillam, S. (2002). *Changing relationships: findings of the patient involvement project*. Retrieved from: www.kingsfund.org.uk.

Gregory, S., bishop, J., and Sheldon, S. (1991) Remembering past events: The Parents Tale. Paper presented to the British Psychological Society Developmental Section Conference, Cambridge.

Hammick M (1996) *Managing the Ethical Process in Research*. Quay Books, Salisbury.

Hampton, J. R., Harrison, M. J., Mitchell, J. R., Prichard, J. S., & Seymour, C. (1975). Relative contributions of history-taking, physical examination, and laboratory investigation to diagnosis and management of medical outpatients. *British Medical Journal*, 2(5969), 486–489.

Haussamen, H. (2016). *Instead of marginalizing others, let's choose empathy*. Last viewed 28 August 2020. https://nmpolitics.net/index/2016/03/instead-of-marginalizing-others-lets-choose-empathy/

Hevner, A. R., March, S. T., Park, J. & Ram, S. (2004) Design Science in Information Systems Research. *MIS Quarterly*, 28, 75-105.

Hibbard, J. H., & Greene, J. (2013). What the evidence shows about patient activation: Better health outcomes and care experiences; fewer data on costs. *Health Affairs*, 32(2), 207–214.

Huckman, R., Stern, A. (2018) *Why Apps for Managing Chronic Disease Haven't Been Widely Used, and How to Fix It*. HBR. [Last viewed 13/01/2021] https://hbr.org/2018/04/why-apps-for-managing-chronic-disease-havent-been-widely-used-and-how-to-fix-it

Hustad, E. and Olsen D. H. (2014), Educating reflective Enterprise Systems practitioners: a design research study of the iterative building of a teaching framework, *Info Systems J*, 5, pages 445–473.

James, W. (1904). *What is Pragmatism. A new name for some old ways of thinking, Writings 1902–1920*. The Library of America. Retrieved from http://www.marxists.org/reference/subject/philosophy/works/ us/james.htm

James, W. (1960) *Pragmatism and four essays from the meaning of truth*. Meridian Books, Inc.

James, W. (1978) *Pragmatism and The Meaning of Truth.* Harvard University Press.

James, JT. (2013). A new, evidence-based estimate of patient harms associated with hospital care. *J Patient Saf* 9:122–8.

Jansen, J, van Weert J, van der Meulen N, van Dulmen S, Heeren T, Bensing J. (2008) Recall in older cancer patients: measuring memory for medical information. *Gerontologist*, 48(2):149-57.

Japp, A., Robertson, C., Wright, R., Reed. M., Robson, R., (2018). *Macleod's Clinical Diagnosis*. 2nd Edition. Elsevier.

Johnson, J., Finn, K. (2017). *Designing User Interfaces for an Aging Population, Towards Universal Design*. Morgan Kaufmann publishers. Elsevier Inc.

Kant, I. (2007[1781]). *Critique of pure reason*. Trans. N. Kemp Smith. London, UK: Palgrave Macmillan.

Kassirer, JP. (1983) Teaching clinical medicine by iterative hypothesis testing. Let's preach what we practice. *N Engl J Med*.309(15):921-923.

Kaufman, J. & Sternberg, R. (2019). *The Cambridge Handbook of Creativity.* Cambridge University Press.

Kessels, R., Patients' memory for medical information. (2003). *J R Soc Med* 96:219–222.

Klein, H.K., & Myers, M.D. (1999) A Set of principles for conducting and evaluating interpretive field studies in information systems. *MIS Quarterly*, 23(1), 67–93.

Koutstaal, W., & Schacter, D. L. (1997). *Intentional forgetting and voluntary thought suppression: Two potential methods for coping with childhood trauma*. In L. J. Dickstein, M. B. Riba, & J. M. Oldham (Eds.), Review of Psychiatry: Vol. 16 (pp. II-79–II-121). Washington, DC: American Psychiatric Press.

Kuhn, T. (1962) *The Structure of Scientific Revolutions*, First edition, University of Chicago Press.

Kuhn, T. (1970) *The structure of scientific revolutions*. Chicago, University of Chicago press., xii, 210-2d, enl.

Lakatos, I. (1978). *The Methodology of Scientific Research Programmes*, Cambridge University Press.

Langewitz W, Ackermann S, Heierle A, Hertwig R, Ghanim L, Bingisser R. (2015) Improving patient recall of information: harness the power of structure. *Patient Educ Couns*., 98:716–21

Lazare, A., Putnam S.M., Lipkin M. (1995) *Three Functions of the Medical Interview*. In: Lipkin M., Putnam S.M., Lazare A., Carroll J.G., Frankel R.M. (eds) The Medical Interview. Frontiers of Primary Care. Springer, New York, NY.

Leape, L.L. (2014). The Checklist Conundrum. *New England Journal of Medicine*, 370, 1063-1064.

Lee, A. S. (1994) Electronic Mail as a Medium for Rich Communication: An Empirical Investigation using Hermeneutic Interpretation. *MIS Quarterly*, 18, 143-157.

Ley, P. (1979). Memory for medical information. *British Journal of Social and Clinical Psychology*, 18, 245–255.

Ley, P. (1988). *Communicating with patients: Improving communication, satisfaction, and compliance*. New York: Croom Helm.

Leyshon, C. (2012). *This Week in Fiction: Mohsin Hamid.* Last viewed 28 August 2020 https://www.newyorker.com/books/page-turner/this-week-in-fiction-mohsin-hamid

Lidwell, W. (2003). *Universal Principles of Design*. Rockport Publishers.

Mackenzie, M., & Knipe, S. (2006). Research dilemmas: Paradigms, methods and methodology. *Issues in Educational Research*, 16(2), 193–205.

Maiochhi, M., (2015). *The neuroscientific basis of successful Design, How Emotions and perceptions matter*. Springer.

Mandler, G. (1967). *Organization and memory*. In K. W. Spence and J. T. Spence (Eds.), The Psychology of Learning and Motivation. New York: Academic Press.

March, S. T. & Smith, G. F. (1995) Design and Natural Science Research on Information Technology. *Decision Support Systems*, 15, 251-266.

Martin, L., Dimatteo M. (2014). *The Oxford Handbook of Health Communication, Behaviour Change, and Treatment Adherence*. Oxford University Press.

McGuire, L. C. (1996). Remembering what the doctor said: Organization and older adults' memory for medical information. *Experimental Aging Research*, 22, 403–428.

McKinstry B1, Watson P, Elton RA, Pinnock H, Kidd G, Meyer B, Logie R, Sheikh A. (2011). Comparison of the accuracy of patients' recall of the content of telephone and face-to-face consultations: an exploratory study. *Postgrad Med J*. 87(1028):394-9.

McPherson, M. L., Smith, S. W., Powers, A., & Zuckerman, I. H. (2008). Association between diabetes patients' knowledge about medications and their blood glucose control. *Research in Social and Administrative Pharmacy*, 4, 37–45.

Mead, N., Bower, P., & Roland, M. (2008). Factors associated with enablement in general practice: Cross-sectional study using routinely-collected data. *British Journal of General Practice*, 58(550), 346–352.

Merriam-Webster (2007) *Merriam-Webster Dictionary*, Merriam-Webster.

Mika, V. S., Wood, P. R., Weiss, B. D., & Treviño, L. (2007). Ask Me 3: Improving communication in a Hispanic paediatric outpatient practice. *American Journal of Health Behavior*, 31 (Suppl 1), S115–S121.

Miller, G. A. (1956). The magical number 7, plus or minus 2 – Some limits on our capacity for processing information. *Psychological Review*, 63, 81–97.

Mingers, J., & Walsham, G. (2010). Toward ethical information systems: the contribution of discourse ethics. *Mis Quarterly*, 34(4), 833-854.

Montgomery, C., Lydon, A., & Lloyd, K. (1999). Psychological distress among cancer patients and informed consent. *Journal of Psychosomatic Research*, 46 (3), 241–245.

Nagle, T., Sammon, D., and Doyle, C. (2016) 'Meeting in the middle: Bridging the practice research divide from both sides', *ECIS 2016: Twenty-Fourth European Conference on Information Systems*, Istanbul, Turkey,12-15 June, AISeL Research Papers, 158 (133pp).

Niehaves, B. (2007) On Epistemological Diversity in Design Science: New Vistas for a Design-Oriented IS Research? *The 28th International Conference on Information Systems (ICIS).* Montreal, Canada.

Nikolov, A., (2017) *Design principle:* Consistency. https://uxdesign.cc/design-principle-consistency-6b0cf7e7339f [last visited 29/11/2018].

Norman D. (2013) *The design of everyday things*. MIT press.

Ong, L. M., de Haes, J. C., Hoos, A. M., & Lammes, F. B. (1995). Doctor–patient communication: A review of the literature. *Social Science & Medicine*, 40, 903–918.

Onwuegbuzie, A.J., Leech, N.L. (2007) Validity and Qualitative Research: An Oxymoron? *Qual Quant* 41, 233–249.

O'Raghallaigh, P., (2011) *Designing an Innovation Modelling Tool to Support Practitioners in the Building of Interactive Theory*. A Thesis Submitted for the Degree of Doctor of Philosophy of the National University of Ireland. (unpublished).

Pachter, L. M. (1994). Culture and clinical care: Folk illness beliefs and behaviours and their implications for health care delivery. *Journal of the American Medical Association*, 271 (9), 690–694.

Pan Y. (2012) Attentional capture by working memory contents. *Can J Exp Psychol*. 64(2):124–128.

Parahoo K (2006) *Nursing Research. Principles, Process and Issues*. 2nd edn. Palgrave Macmillan, Basingstoke.

Parikh, N. S., Parker, R. M., Nurss, J. R., Baker, D. W., & Williams, M. V. (1996). Shame and health literacy: the unspoken connection. *Patient Education & Counseling*, 27 (1), 33–39.

Parkes CM (2006) Guidelines for conducting ethical research in psychosocial issues in palliative care. *Indian Journal of Palliative Care* 12(1): 17–21

Peffers, K., Tuunanen, T., Gengler, C. E., Rossi, M., Hui, W., Virtanen, V. and Bragge, J. (2006), "The design science research process: a model for producing and presenting information systems research", in Proceedings of the first international conference on design science research in information systems and technology (*DESRIST* 2006), pp. 83-106.

Peirce, C. S. (1958). *How to make our ideas clear*. In P. P. Weiner (Ed.), Charles S. Peirce: Selected writings (pp. 113–136). New York, NY: Dover.

Personal Injury Team Ireland (2017). *Medical Negligence in hospitals in Ireland*. http://www.personalinjuryireland.ie/medical-negligence-in-hospitals-in-ireland.

Peterson, MC, Holbrook JH, Hales DV, et al. (1992) Contributions of the history, physical examination, and laboratory investigation in making medical diagnoses. *West J Med*. 156:163–165.

Piper, H. and Simons, H. (2005) '*Ethical responsibility in social research'*, in B. Somekh and C. Lewin Research Methods in the Social Sciences, London: Sage.

Popper, Karl (1959). *The Logic of Scientific Discovery.* Abingdon-on-Thames: Routledge.

Popper, K. (1989). *Conjectures and refutations: The growth of scientific knowledge*, Revised Edition. London, UK: Routledge.

Powell, T. C. (2001). Competitive advantage: logical and philosophical considerations. *Strategic Management Journal*, 22(9): 875–88.

Prigge, A., Dietz, B., Homburg, C., Hoyer, W., Burton, J., (2015) Patient empowerment: A cross-disease exploration of antecedents and consequences, *International Journal of Research in Marketing*, Volume 32, Issue 4.

Pulvirenti, M., McMillan, J. and Lawn, S. (2014), Empowerment, patient centred care and self-management. *Health Expectations*, 17: 303-310.

Quittner, Alexandra L.; Saez-Flores, Estefany; Barton, John D. (2016) The psychological burden of cystic fibrosis. *Pulmonary Medicine*: March 2016 - Volume 22 - Issue 2 - p 187–191.

Ratjen, F., Bell. S.C., Rowe, S.M., Goss, C.H., Quittner, A.L., Bush, (2015) Cystic fibrosis. *Nature Reviews Disease Primers*. 1:15010.

Redman, T. (2016) *Getting in Front on Data: Who Does What*. Technics Publications.

Renzetti, Claire M. and Lee, Raymond M., "*Researching Sensitive Topics*" (1993). CRVAW Faculty Book Gallery. 14.

Rubin DC. (1982) On the retention function for autobiographical memory. *Journal of Verbal Learning and Verbal Memory*, 21, 21-38.

Rubin, D., Umanath S., (2015) Event Memory: A Theory of Memory for Laboratory, Autobiographical, and Fictional Events. *Psychol Rev*. 122(1): 1–23.

Safeer, RS, Keenan J. (2005). Health literacy: the gap between physicians and patients. *Am Fam Physician* 72:463-8.

Sandler, G. (1980). The importance of the history in the medical clinic and the cost of unnecessary tests. *Am Heart J*. Dec;100(6 Pt 1):928-31

Sarkar, U., Schillinger D., Bibbins-Domingo K., Nápoles A., Karliner L., Pérez-Stable E., (2011) Patient–physicians' information exchange in outpatient cardiac care: Time for a heart to heart? *Patient Education and Counseling*, Volume 85, Issue 2, Pages 173-179.

Schon, D. A. (1983). *The reflective practitioner: How professionals think in action* (Vol. 5126). New York: Basic books.

Schraa, J., Dirks J., (1982) Improving patient recall and the comprehension of the treatment regime. *Journal of Asthma*, 19(3), 159162.

Schwesinger, B., (2010). *The Form Book, Best Practice in Creating Forms for printed and online use*. Thames & Hudson.

Sein, M., Henfridsson, O., Purao, S., Rossi, M., & Lindgren, R. (2011) Action design research. *MIS Quarterly*, 35(1), 37–56.

Shapiro, D. E., Boggs, S. R., Melamed, B. G., & Graham-Pole, J. (1992). The effect of varied physician affect on recall, anxiety, and perceptions in women at risk for breast cancer: An analogue study. *Health Psychology*, 11, 61–66.

Sibbald, M., de Bruin, A.B.H., Yu, E., van Merrienboer JJ. (2015). Why verifying diagnostic decisions with a checklist can help: insights from eye tracking. *Adv in Health Sci Educ*.20: 1053.

Simmons, M., Chew I., (2015) *How to Create A Checklist*. http://www.beseminal.com/wp-content/uploads/2015/11/HowToCreateAChecklistFinal.pdf [Site Last visited 29/11/2018].

Simon, H. A. (1996) *The Sciences of the Artificial*, Cambridge, MA., USA, MIT Press Books.

Solet, DJ, Norvell JM, Rutan GH, Frankel RM. (2005). Lost in translation: challenges and opportunities in physician-to-physician communication during patient handoffs. *Acad. Med* 80:1094–9.

Stahl, B. C., Eden, G., Jirotka, M., & Coeckelbergh, M. (2014). From computer ethics to responsible research and innovation in ICT: The transition of reference discourses informing ethics-related research in information systems. *Information & Management*, 51(6), 810-818.

Stahl, B. C., Timmermans, J., and Mittelstadt, B. D. (2016). The ethics of computing: A survey of the computing-oriented literature. *ACM Computing Surveys* (CSUR), 48(4), 55.

Sternberg, RJ. (2009) *Cognitive Psychology*. 5th Ed. Belmont (BE): Wadsworth Cengage Learning.

Stock, C., Sundt T., (2015) Timeout for Checklists? *Annals of Surgery* _ Volume 261, Number 5.

Tulving, E., Pearlstone, Z. (1966) Availability versus accessibility of information in memory for words. *Journal of Verbal Learning and Verbal Behaviour*, Volume 5, Issue 4, p.381-391.

Turilli, M., and Floridi, L. (2009). The ethics of information transparency. *Ethics and Information Technology*, 11(2), 105-112.

Turner, J., & Kelly, B. (2000). Emotional dimensions of chronic disease. *Western Journal of Medicine,* 172(2), 124–128.

Vaishnavi, V., Kuechler, W., and Petter, S. (Eds.) (2004/19). "*Design Science Research in Information Systems*" January 20, 2004 (created in 2004 and updated until 2015 by Vaishnavi, V. and Kuechler, W.); last updated (by Vaishnavi, V. and Petter, S.), June 30, 2019. URL: http://www.desrist.org/design-research-in-information-systems/.

Varelius J. (2006). The value of autonomy in medical ethics. *Medicine, health care, and philosophy,* 9(3), 377–388.

Vitruvius, Pollio. transl Morris Hicky Morgan (1960) The ten books on architecture. Courier Dover Publications.

von Hippel, E., Euchner, J. (2013) User Innovation. *Research-Technology Management,* 56:3, 15-20,

Watson, PW, McKinstry B., (2009). A systematic review of interventions to improve recall of medical advice in healthcare consultations. *J R Soc Med,* 102:235-43.

Webster, J., & Watson, R. (2002). Analyzing the Past to Prepare for the Future: Writing a Literature Review. *MIS Quarterly,* 26(2).

Weiser, T.G., Haynes A.B., Lashoher A., Dziekan G., Boorman D.J., Berry W.J., Gawande A.A., (2010). Perspectives in quality: designing the WHO Surgical Safety Checklist, *International Journal for Quality in Health Care*, Volume 22, Issue 5, 1, Pages 365–370.

Wheatley, MJ. (2002). *It's an Interconnected World.* Available from: https://margaretwheatley.com/articles/interconnected.html

White CS, Mason AC, Feehan M, et al. (1995) Informed consent for percutaneous lung biopsy: comparison of two consent protocols based on patient recall after the procedure. *AJR Am J Roentgenol* 165:1139e42.

Whiting LS, Vickers PS. Conducting qualitative research with palliative care patients: applying Hammick's research ethics wheel. *Int J Palliat Nurs*. 2010 Feb;16(2):58, 60-2, 64-6, 68.

Wieringa, R. (2010) Relevance and Problem Choice in Design Science. *The 5th International Conference on Design Science Research in Information Systems and Technology (DESRIST).* St. Gallen, Switzerland.

Wolfe, J. M. (1994). Guided Search 2.0: a revised model of visual search. *Psychonomic Bulletin & Review,* 1, 202–38.

Wong, PTP (2014) *Self Reflection* Available from: https://paultpwong.wordpress.com/2014/09/22/self-reflection-2/

World Health Organisation. (2010) *New scientific evidence supports WHO findings: a surgical safety checklist could save hundreds of thousands of lives.* Available from: http://www.who.int/patientsafety/safesurgery/checklist_saves_li

World Medical Assembly (1989) *Declaration of Helsinki*. World Medical Association, Helsinki.

Appendices

Appendix A

Paper 1: A Check List Designed to Improve Information Recall Among CF Patients

A.1 Abstract

When a Cystic Fibrosis (CF) patient/carer meets a doctor, it is the responsibility of the patient/carer to recall their medical history. Often the information imparted by the patient/carer is inaccurate due to their inability to remember their medical history accurately. Coupled with this, patients/carers often leave medical encounters unable to remember the information that has been imparted to them. These memory issues can seriously impede the doctor's ability to correctly diagnose and treat a CF patient, and the patient's ability to adhere to the doctors' recommendations.

This paper explores: "*The Memory Recall of mild to moderate Cystic Fibrosis (CF) patients/carers in routine doctor's appointments and the impacts a simple artefact can have on memory recall, stress and empowerment*". Using Design Science Research, the artefact designed, built, and evaluated to address the problem is a pretotype (a paper-based prototype) in the form of a check list.

Rigorous evaluation by CF patients, carers and respiratory clinicians' points to the artefact's validity and shows its contribution to memory recall, a reduction in stress,

and an increase in empowerment for both CF patients and carers. The insights gained from this research will be an essential precursor to the creation of an effective digital solution.

Keywords:

Design Research, Information Recall, Cystic Fibrosis, Check List, Stress, Empowerment, Pretotype.

A.2 Introduction

Cystic Fibrosis (CF) is an inherited chronic respiratory disease that primarily affects the lungs and digestive system. The underlying genetic defect is related to the cystic fibrosis transmembrane conductance regulator (CFTR), which leads to an imbalance in the exchange of salt and water across the cell membrane. This affects all mucus generating organs, including the pancreas, sinuses, and reproductive system (Ratjen et al., 2015). Although CF is a multi-organ disease, the cycle of inflammation coupled with infection and repeated pulmonary exacerbations (primarily affecting the lungs) is a major cause of morbidity and mortality (Ratjen et al., 2015). Coupled with the physical aspects of the disease, CF centred studies report rates of anxiety ranging from 30-33% among CF adults (Yohannes et al., 2012) and 38% among CF carers (Besier et al., 2011).

The understanding and remembering of health information is a key component in healthcare management. The context of the medical appointment and of hospitals in general can render effective doctor–patient interaction difficult due to appointments often taking place under severe time pressures and under high stress levels (Ong et al., 1995). High levels of stress and anxiety in turn hinder recall of medical information (Ley, 1979; Shapiro, 1992). Encoding information at a time of distress and possible confusion can impair patients' capacity to recall information, as is inferred by studies of the harmful impact of stress on eyewitnesses (c.f. Deffenbacher et al., 2004). This papers objective is to explore: "*The Memory Recall of mild to moderate Cystic Fibrosis (CF) patients/carers in routine doctor's*

appointments and the impacts a simple artefact can have on memory recall, stress and empowerment".

We investigate how features, such as colour and information structuring (information organised or bound together in a meaningful way facilitating higher order cognitive representations), might be used in the design of an artefact to aid the memory recall of CF patients/carers. We do this exploration by means of Design Science Research using a check list as a specific form of paper-based prototyping (referred to here as pretotyping).

In this paper we focus on the specific concept of memory recall rather than general communication between a doctor and CF patient or carer. While there are many studies (primarily by clinicians) on how well patients can recall what the doctor has imparted to them *during* their medical appointment, the uniqueness of our research is that it looks at the problem of memory recall from a CF patient /carer perspective. We examine the ability of the patient/carer to recall the health events they have experienced outside of the medical appointment setting and their ability to recall this information accurately when asked to do so by their clinician, which according to Cohen et al. (1995) and Martin et al. (2014) has received a lot less attention in research.

A further uniqueness of this study is that the lead author draws on his own experience as a CF patient, living with the disease for over 46 years. These experiences significantly shape both the research and the design of the artefact.

The remainder of this paper is structured as following: a brief background of the study, followed by an outline of the development and evaluation of the artefact. We

then highlight the key benefits and finally we conclude our paper with the limitations of this study and our contributions to knowledge.

A.3 Background to the study

The main nexus of communication between the patient and the doctor is the medical appointment. The conversation in an appointment is bi-directional and consists of two important phases - the *elicitation* phase and the *explanatory* phase. Both phases can be problematic for the CF patient or carer in terms of their ability to remember information. In addition, we look at processing capacity, information structuring and colour and their impacts on memory recall.

A.3.1 Elicitation phase

The *elicitation* phase of the appointment is when the clinician interviews the patient/carer regarding their medical history, current wellbeing, current medication, and so on (Sarkar et al, 2011; Martin et al., 2014). This is the kind of detailed information that a doctor requires to formulate an accurate diagnosis and to engage in clinical decision-making (Cohen et al., 1995). This "*Clinical History and Interview*" stage accounts for 46% of the duration of a doctor's appointment (Bickley, 2013). Oftentimes the information imparted by the patient/carer is inaccurate due to their inability to remember their medical history accurately (Cohen et al., 1995). Indeed, this inability to remember relevant clinical information often results in patients and carers becoming more anxious in what is already a demanding environment. This correlates well with our study of 305 CF participants in 2015, where 74% said they found recalling their medical history at a doctor's

appointment a stressful experience (Twomey, 2015). The overall profile of a CF patient's condition is a key factor in their long-term care, quality of life and their life expectancy (Twomey, 2015). Imprecise data can have several pernicious effects on the treatment the patient receives. A misdiagnosis may see the likelihood of recovery substantially diminished, and an erroneous diagnosis of a serious illness can cause considerable mental distress, psychological problems, or death (Personal Injuries Ireland, 2017).

A.3.2 Explanatory Phase

The second phase of the appointment is the *explanatory* stage, in which doctors engage in informing patients about diagnoses, further clinical options, self-management plans as well as general advice (Martin et al., 2014). Memory recall has been reported to be a predictor for adherence and other self-care behaviours such as lifestyle modification (McPherson et al., 2008). Research shows however that the bulk of patients fail to recall the information they are given *during* their medical encounters leading to reduced health outcomes, diminished patient satisfaction and to clinician dissatisfaction (Schraa et al., 1982).

A.3.3 Processing Capacity

Human working memory is limited in the number of items it can hold. Processing capacity (e.g., processing speed, working memory) limits the efficacy of many knowledge processes (Chin et al., 2017). In his landmark analysis, Miller (1956) observed that humans can recall only seven plus/minus two units (or 'chunks') of information. Moreover, there also seems to be a linear correlation between the amount of information provided and the amount that can be recalled (Safeer et al.,

2005). Predictably, the more information provided, the more information is lost (ibid).

A.3.4 Information Structuring

Psychological theory and associated empirical findings suggest that information structuring can be an effective instrument in improving recall and comprehension (Ackermann et al., 2016). The relationship between structure and ensuing recall performance has hitherto been studied albeit in very diverse situations such as education and Schizophrenia (Epstein, 1967; Hannafin, 2004; Traupmann, 1975). In particular, information appears easier to store in memory when it is structured in a way that assists the recipients' organisation of it (Langewitz et al., 2015).

From a cognitive perspective the advantages of information structuring seem to be in "*chunking*"; that is, low-level separate fragments of information are joined together into larger high-level meaningful units (Miller, 1956). It also seems that implicit categorisation i.e., merely presenting the data in a logical order does not improve memory recall. By contrast, explicit categorisation does increase recall of medical information by patients (Kessel, 2003). Nevertheless, as patients age the organisation of data seems less important to memory function than the degree to which the information is consistent with their previously acquired knowledge and beliefs (Hess and Tate, 1991).

A.3.5 The Role of Colour

The role played by colour in augmenting our attention level is conclusive (Pan, 2012; Eysenck, 2009) as colours have an ability to attract our attention (Farley et

al., 1976). The more attention dedicated to particular stimuli, the greater the probability that the stimuli will be transferred to longer lasting memory storage (Sternberg et al., 2009). Colour therefore has the capability to increase the prospect that environmental stimuli will be encoded, stored, and retrieved effectively. The selection of colours and the manipulative facets can, however, shape the degree to which colours can affect human memory performance (Dzulkifli et al., 2013). The right combination of colours is important because it can produce higher level of contrast, and this can affect memory retention (Dzulkifli et al., 2013). Colours can also impact the level of interest, and also give rise to emotional stimulation which contributes to control activities that will subsequently improve memory execution (Kaya et al, 2004). Stimulation, especially emotional arousal, can play a vital role in retaining the information in the memory system. Indeed, colours can heighten the relationship between arousal and memory (Kaya et al, 2004).

A.4 The Check List and its Evaluation

Experts have long documented the capacity for human failure in complex environments (Arriaga et al., 2013). Check lists are a conventional instrument for averting human errors in complicated, high intensity areas of effort (Borchard et al., 2012). In fields such as aviation or aeronautics the use of check lists is extensive and stretches back more than 30 years. Their use in the discipline of medicine is relatively recent, but they have proven to be very beneficial in preventing memory failures (Stock et al., 2015). For example, when implemented correctly, check lists can substantially diminish cumulative errors that lead to surgical omission and they can significantly augment patient safety (WHO, 2010). In January 2007, in an

endeavour to tackle the safety of surgical care, the World Alliance for Patient Safety began efforts on the World Health Organisation's (WHO) Safe Surgery Check List (WHO, 2008). Haynes et al. (2009) conducted an investigation that discovered that surgical deaths were lessened by approximately one-half and surgical impediments were diminished by more than one-third when the surgical safety Check List was put into operation. As crisis associated cognitive aids it made sense for our study to explore the use of a check list to aid memory recall in the appointment setting. In our literature review we did not discover any research that focuses on the design or use of check lists for CF patients and carers (or for any other chronic illnesses).

Pretotyping is a paper-based approach developed by Alberto Savoia (2011) at Google to understand why products/services fail in their proposed settings despite being well designed. Like functional prototyping, pretotyping develops a scaled down form of a product. However, in contrast to functional prototyping, which focuses on questions such as: "*Can we make it?*", "*Will it function as anticipated?*", "*How economically can we make it?*", pretotyping focuses on questions such as "*Will people be attracted to it?*", "*Will they purchase it if we make it?*", "*Will they use it as we first thought?*", "*Will they continue to use it?*" (Savoia, 2011). Pretotyping is useful in investigating the initial interest and actual usage of an impending digital solution by simulating its core experience (in our case *within* the medical appointment) with the smallest investment of time and money feasible. Pretotypes support the capture of distinctive insights from users of the pretotype within a given context and also help avoid "*falling in love*" with early solutions.

The pretotype in this study takes the form of a check list, designed for the CF patient/carer to fill out *before* and *during* the doctor's appointment. The pretotype evolution took place over a ten-month period where the researchers adopted a Design Research (DR) approach to its design, build and evaluation. DR is essentially a problem-solving paradigm (Hevner et al., 2004). DR helps resolve new or wicked problems by crafting innovative artefacts (Peffers et al., 2007). The Design and Build team consisted of a CF patient (the lead author), a CF respiratory clinician and two carers of CF children.

A core element of Design Research is the evaluation of the artefact being developed. The check list in this study was evaluated in order to determine how well expectations (aiding memory recall both *during* and *after* a medical appointment) and intentions (reducing stress and increased empowerment) were meet. The full list of evaluation criteria is listed in Table A-1. The participants in our evaluation group consisted of seven CF adult patients and eleven carers of CF children. The check list evolved over three iterations, where each of the three versions of the check list was evaluated in real life routine doctors' appointments by each of our participating evaluators. Each participant was interviewed by the research team. In addition, expert opinion was sought from clinicians on the effectiveness of the check list design and its subsequent use by CF patients or carers. Next, we describe each version of the check list.

Table A-1 Evaluation Criteria

Evaluation Criteria for Each Version		
Criteria	**Definition**	**Details**
Completeness	Ensuring that all necessary (and appropriate) sections, including individual items/metrics required by a CF patient or carer at their medical appointment are included in the Check List.	We will seek to make sure that all key **CF related metrics** i.e. FeV1, medications, O2 saturation etc are included within the Check List. To do this we will need CF patients/carers that are using the Check List in real appointments, to tell us what is missing. We will also obtain advice from our clinicians. This makes sense as some health metrics can be more relevant with disease type, age and disease progression. For example, an adult with CF may have their cholesterol measured routinely, whereas with a child their height and weight metrics may be more important at a particular time.
Usability	The degree to which the artefact is able or suitable to be used in the medical appointment. How logical is it? How does it functions visually. Is it difficult to use? Is the CF patient or carer comfortable using it?	Cognition and emotion are tightly intertwined, which means the designer must design with both in mind (Norman, 2013). While the Check Lists purpose will be to aid memory recall, reduce stress and increase empowerment within a complex and demanding setting. We need to ensure that the Check List helps CF patients/carers and does not hinder them within the appointment or after they leave the clinic. We will ask them for their feedback after using the Check List. We will ask them what issues they have, we will also ask them to rate the Check List in terms of ease of use, how well it functions from a visual perspective, how logical it is and if they are comfortable using it. This subjective feed back will be ascertained using a Likert scale, scaling responses from 1 to 5.
Robustness	The ability of the Check List to withstand or overcome adverse conditions, rigorous testing and to have CF patients and carers continue to engage and use the artefact within their medical appointments.	Much of the failure to achieve optimal health outcomes is often due to the failure of health actions themselves – that is, individuals' adherence (or nonadherence to healthy behaviours and treatment routines (Martin, 2014). We hope that our solution will really resonate with CF patients and carers and really take hold. That they will continue to use the Check List, as it satisfies their memory recall needs, is aligned with their goals and can become automatic with little or no effort. Therefore, our robustness questions will focus around their usage behaviour. Have they changed their behaviour moving from nothing or a diary to using the Check List? Do they continue to use it over time? Have they noticed changes in their own behaviour and what changes have they made?
Impact	We will require CF patients and carers subjective opinion on the effect the Check List has on their perceived stress levels, on their sense of empowerment and on their ability to remember during and after the medical appointment.	Over the last number of years, empowerment and empowerment-related themes, such as patient activation, enablement and involvement, have really come to the fore. In tandem with this our CF patients and carers report increased stress levels during and after their medical appointments due to memory recall issues making them feel inadequate, helpless and sometimes frustrated. Therefore, we will need to understand the effects that the Check List is having on these variables reported by patients/carers as important to them. This will be done using a Likert rating scale (1-5). We will hope to achieve scores of 4 or 5 for both stress reduction , increased empowerment and improved memory recall.

A.4.1 Check List Version 1

A design workshop was held in September 2016 by our Design and Build team. As recommended by experts in the area of check list design (such as Simmons & Chew, 2015) we sought to make our check list complete, usable, robust, and impactful. We also kept to the point, keeping the volume of information to a minimum as recommended by Baddeley (2007). Our focus was on ensuring the check list was easy to use in the pressurised appointment environment. We sought to maximise patient comprehension and make the capture of health information as simple as possible (e.g., by decreasing reading level for those participants with a lower educational background), without missing key context and connotation (Schraa et al., 1982), affording cues of the most crucial steps (i.e., the killer items). See Table A-2 below for the Design and Build of each version.

Drawing on over 100 years of combined CF experience in the Design and Build team, we created defined sections/categories within our check list, limiting pre-population to essential data, and consolidating other items of interest into a small number of fields to harness the power of structure as an aid to memory recall it (c.f. Langewitz et al., 2015). We designed the check list around the communication clinical workflow of the medical appointment (i.e., the step-by-step data collection/instruction process that a clinician engages in at a medical appointment) as outlined by Bickley (2013). This use of categorisation was first noted by Ley (1979) who recommended using explicit categorisation as an aid to memory recall.

Table A-2 Design and Build of each Version

Problem	**"Exploring Memory Recall of mild to moderate Cystic Fibrosis (CF) patients/carer in a routine doctor's appointment"**		
Build	**Version 1**	**Version 2**	**Version 3**
	Date: Sept 2016	**Date:** Nov 2016	**Date:** March/April 2017
	This Check List (Appendix E) was decided upon due to it suitability in complicated, high intensity areas of effort (Borchard et al., 2012) and due to its ability in preventing memory failures in medicine (Stock et al., 2015). It was agreed that when in the doctor's appointment communicating with a pen and sheet was more appropriate than having "one's head in an iPad" etc. The Design and Build team held several workshops which involved scenario type /role playing to augment our understanding of patient/carer behaviour and journey mapping to help visualise the patient's experience. Research literature was used to guide the Design and Build team in the creation of the Check List, in particular works by Borries Schwesinger (2010) a renowned expert in the field of form/visual creation. On release of the Check List a detailed Check List of usage instructions was given to each participant.	Following the evaluation of Version 1 the Design and Build team consulted with literature and several design and build sessions were held. The team applied their research findings regarding the use of colour in aiding memory recall (c.f. Wichman et al., 2002) and also as advised by Elliot et al., (2015) the team used combinations of colour to create higher levels of contrast, to influence memory. Missing CF related metrics were also added to achieve greater completeness. The Check List (see Appendix L) was again supplied with revised detailed usage instructions.	The main problem areas that were identified in Version 2, that of space and the absence of an emotional section (as requested by some of our participants) were addressed in Version 3. We sought advice from one of our clinicians on how we would address the request for an emotional section in the Check List. Check List Version 3 (see Figure A-1) was released with revised usage instructions.

We released Version 1 (Appendix E) of the check list together with detailed usage instructions to our eighteen CF patients/CF carers, who then used it at their subsequent medical appointments. We were interested in ascertaining how they would use the check list, and most importantly how the check list would meet the evaluation criteria and ultimately assist in increasing memory recall, reducing stress, and increasing empowerment.

Summary of Findings

Previous to our research, only 17% of our participants were capturing their medical data at their medical appointments and none of them were using any applications, as they felt that there was nothing available that matched the needs of a CF patient or carer. Our evaluation (see Table A-4) shows 81% of participants reported an increase in memory recall as a result of using the check list at their respective medical appointments. This was not altogether surprising as research has shown that better recall in structured conditions can be attributed to "*chunking*'': the ability to form high-level clusters of information from low-level individual elements (Gobet, 2001; Chen, 2005; Li, 2013). However, following our participant interview process we discovered that the monochrome colour in the check list was causing some issues. For example, a young mother (already in a heightened state of stress with a sick 3-year-old CF child) reported becoming distracted by her child's coughing spasm *during* an appointment and found it difficult to relocate her attention back to the correct section of the check list. Our interviews also revealed that important CF related metrics such as blood sugars, bone density, and liver readings were omitted from the check list.

A.4.2 Check List Version 2

Colour is believed to be the most significant visual experience to human beings (Adams et al., 1973). As mentioned, the monochrome colour was causing a usability issue for our CF patients and carers. Guided by the literature, the Design and Build team discovered not only how we might use colour better to solve our usability problem but also that colour could function as a powerful information channel to the human cognitive system and could play an important role in improving memory function (c.f. Wichman et al., 2002). The Design and Build team colour coded each section of the check list using particular combinations of colour as advised by Elliot et al. (2015) and Schwesinger (2010). The right combination of colour is important because it can produce a higher level of contrast, and this can influence memory retention (Hall, 2004). In addition, the identified CF related metrics previously overlooked were added. At the end of November 2016, we released Version 2 (Appendix L).

Summary of Findings

In Version 2 there was a 19% increase in completeness (Table A-4). 72% of the evaluation group also commented positively on the bright pink and green colours at the end of the artefact. They felt that the use of colour in this way had aided their ability to recall information and had helped them avoid leaving an appointment without asking important questions or highlighting key concerns that the patient or carer had. This aid to the patients/carer's memory recall is not surprising given the use of colour to treat patients with Alzheimer Disease (a neuro-degenerative form of dementia which deteriorates memory capabilities) (Dzulkifli et al., 2013). In

1976, Farley and Grant began experiments on the influence of colour on attention and discovered that coloured multimedia presentations resulted in better attention and memory performance. Colour was used in the check list in order to draw the patient's attention to certain sections – such as the 'Questions for the doctor' and the 'Comments by the doctor'. The following comment made by one of the carers was also very encouraging "*My son who is 13 years old can fill it out*". This showed an increase in the usability of the check list. For individuals to change their everyday behaviours it can be challenging, difficult to achieve, expensive and the impacts are often short-lived (Kvedar et al., 2015). Our check list was demanding behavioural changes, which required doing new things (e.g. filling in certain sections of the check list *before* the appointment, acting somewhat like a rehearsal for the appointment, which in itself aids memory recall (White et al., 1995), doing things better (e.g. asking the doctor more questions to enable sections of the check list to be completed *during* the appointment) and halting certain behaviours (e.g. guessing/estimating in response to questions posed by the doctor at appointments, due to an inability to remember facts).

The coded comments in Table A-3 were made by some of the evaluators indicating increased empowerment and engagement (by the individuals in their own or their child's health). However, some limitations of the check list were also being called out, including the need to capture data between appointments (for example in the home). Other questions pointing to limitations in the current design included: How could insights be gained from all the check list data collected? Where should completed check lists be kept? How should they be backed up? The Design and Build team agreed that it was now time to understand more about the real "*impacts*"

that the check list was having. In addition, it was decided that the time was right to comprehend what CF clinicians had to say about this new artefact *within* the appointment setting.

Table A-3 Patient comments at interviews following use of Version 2 of Check List

Impact Type	Participant Type	Example of quotes
Empowerment	Carer	*"Now I ask way more questions, and I feel I am getting way more out of my appointment with the doctor"*
Empowerment	Patient	*"It prompts me to ask about x-rays reading etc."*
Empowerment	Patient	*"For me it's the amount of preparing, looking over notes etc. I am forced to think more"*

A.4.3 Check List Version 3

Further sections such as emotional state of our CF patients and carers were added to the check list in Version 3 (Figure A-1) and the space issues identified were also addressed. Our evaluations for Version 3 (Table A-4) took place in late March/early April 2017. As a result of using the check list and now being able to recall and relay information more easily, CF patients and carers felt less stressed and more empowered. This is discussed in greater detail in our next section where we present the key benefits of the check list in relation to the research objective.

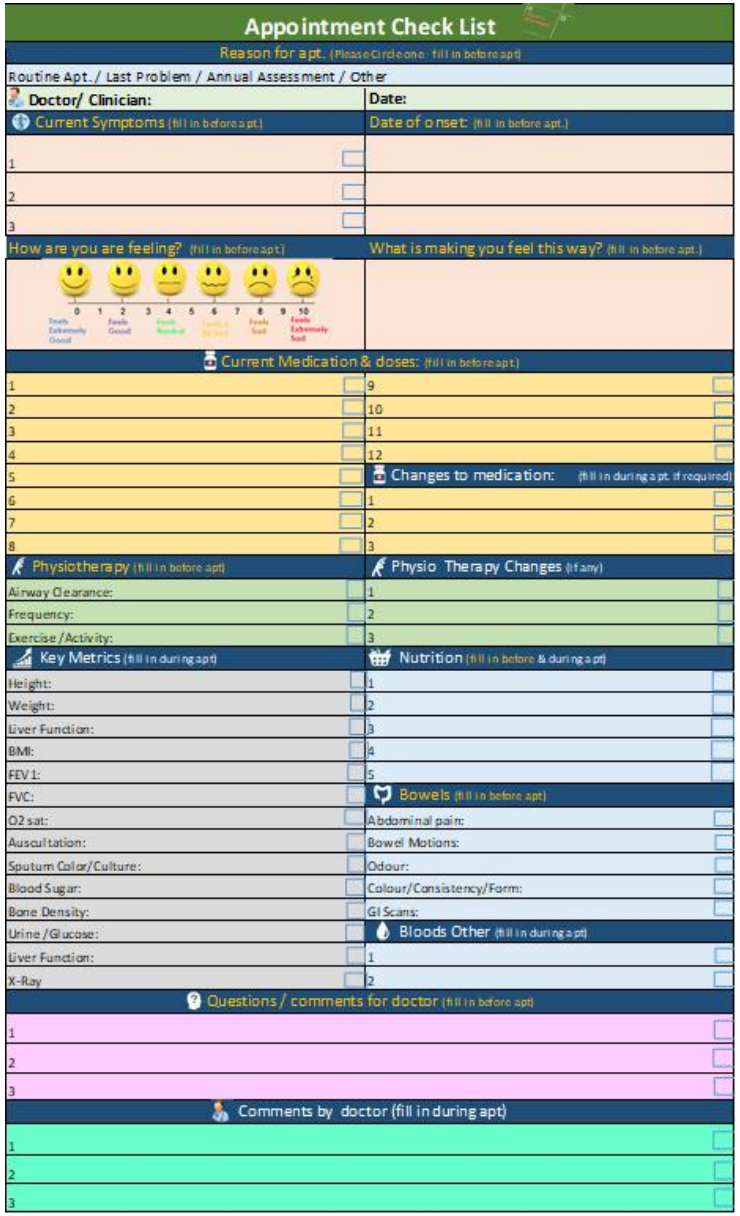
Summary of Findings

As per Table A-4 our evaluations were looking more positive with higher levels of completeness, usability, and robustness. The comments made in terms of the impacts the check list was having (Tables A-5 & A-6) were both moving and very

encouraging. However, another challenge also came to the fore which hitherto had not being expressed but is not altogether surprising. What if a person does not have a printer or a colour printer? This would be solved by getting a booklet of check lists printed in colour (which could detach easily if required) which would then be given to each CF patient or carer for use.

A.4.4 Expert Clinical Opinions

We sought the views of two CF clinicians on check list Versions 2 & 3 which had been used in appointments with them. One of the clinicians, who was head of adult respiratory medicine in his hospital, commented, "*I think the check list is a great idea and should really make a difference to appointments*". Also, the lead author visited the Paediatric team in the same hospital in early 2017. Although initially cautious of the check list (as had previously been reported by carers) and of supplying carers with medical information, the Paediatric unit are now actively providing carers with their child's medical data to help them record their medical data on their check lists. This is a big win as it shows great promise for much needed evidence of behavioural changes by some clinical stakeholders. Research shows that even in successful hospitals, there are doctors who oppose partaking in check list implementation primarily due to the perception that it takes up too much of their time (Leape, 2014). It seems that the level to which a check list can impact processes of healthcare and patient outcomes can hinge on attitudes and behaviours of all stakeholders (Rosen et al., 2014).



Appointment Check List

Reason for apt. (Please Circle one - fill in before apt)

Routine Apt. / Last Problem / Annual Assessment / Other

Doctor/ Clinician: | Date:

Current Symptoms (fill in before apt.) | Date of onset: (fill in before apt.)

1
2
3

How are you feeling? (fill in before apt.) | What is making you feel this way? (fill in before apt.)

0 Feels Extremely Good | 1 2 Feels Good | 3 4 Feels Neutral | 5 6 | 7 8 Feels Sad | 9 10 Feels Extremely Sad

Current Medication & doses: (fill in before apt.)

1 2 3 4 5 6 7 8 9 10 11 12

Changes to medication: (fill in during apt. if required)

1 2 3

Physiotherapy (fill in before apt) | Physio Therapy Changes (if any)

Airway Clearance:
Frequency:
Exercise /Activity:

1 2 3

Key Metrics (fill in during apt) | Nutrition (fill in before & during apt)

Height:
Weight:
Liver Function:
BMI:
FEV 1:
FVC:
O2 sat:
Auscultation:
Sputum Color/Culture:
Blood Sugar:
Bone Density:
Urine /Glucose:

1 2 3 4 5

Bowels (fill in before apt)

Abdominal pain:
Bowel Motions:
Odour:
Colour/Consistency/Form:
GI Scans:

Bloods Other (fill in during apt)

Liver Function:
X-Ray

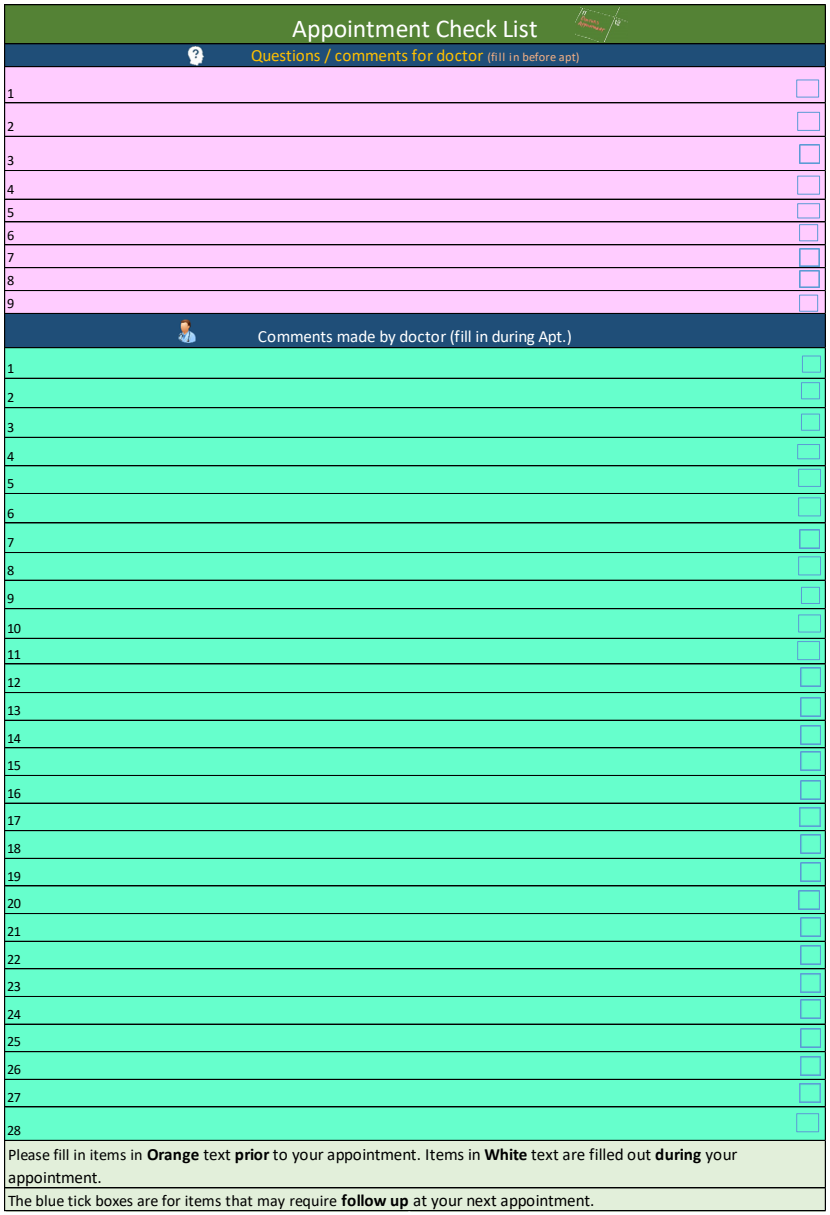
1 2

Questions / comments for doctor (fill in before apt)

1
2
3

Comments by doctor (fill in during apt)

1
2
3



Appointment Check List

Questions / comments for doctor (fill in before apt)

1 2 3 4 5 6 7 8 9

Comments made by doctor (fill in during Apt.)

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28

Please fill in items in **Orange** text **prior** to your appointment. Items in **White** text are filled out **during** your appointment.

The blue tick boxes are for items that may require **follow up** at your next appointment.

Figure A-1 Check List Version 3

Table A-4 Evaluation of each version

Check List Evaluation Summary				
	Metric	**Version 1** **Date:** Oct 2016 - Nov 2016	**Version 2** **Date:** Jan 2017 - Feb 2017	**Version 3** **Date:** Mar 2017
Intervention & Evaluation	**Completeness**	61% completeness achieved in terms of key information that needed to be recorded for recall purposes. Identified gaps in the Check List Completeness i.e. urine tests, bone density, sugar levels etc.	High scores of over 80% in completeness were achieved, albeit with further work to be done in the area of medication and emotional state metrics.	Met evaluation goals for Completeness (100%) in terms of key information that needed to be recorded for *recall* purposes for CF patients and carers.
	Usability	100% were comfortable using the sheet, but we identified a major usability issue regarding the uniformity of colour which was hindering the use of the Check List in the pressurised environment of the appointment. Participants reported having difficulty finding their way back to particular sections (quickly) if they were distracted in an appointment. 100% of participants claimed they were however comfortable using the Check List in their appointment.	High scores of over 80% in usability but space requirements were raised as an issue. As expected, the use of colour to separate the sections really added to the usability of the Check List where it was now found to be more logical, simpler to use and easier to find one's way back to a particular section if distracted. 17/18 participants give a 4 or 5 out of 5 in terms of ease of use.	Met evaluation goals for Usability 95% in the pressurised environment of the medical appointment facilitating *information recall*.
	Robustness	Recognition by 78% of participants that a change in behaviour would be required and also a commitment by 94% to change behaviour in the future if the issue of *information recall* was to be addressed using the Check List	High degree of robustness (albeit with some engagement techniques required for 3/18 of the Group). Recognition now by 83% of participants that they would need to change their behaviour in the future if the issue of *information recall* was to be solved using the Check List.	15/18 of participants were using the Check List in all appointments for *information recall* with the remaining 3 requiring the use of engagement techniques to keep involved.
	Impacts	100% of the participants felt that the Check List had aided them in some way in their respective medical appointments, especially in their ability to *remember data.*	Early signs of increases in Empowerment and Engagement by participants.	In Version 3 we sought to really understand the Impacts that the sheet was making in appointments and on the CF patient/carers who had now been using the Check List (albeit in different forms) for almost six months. Impacts are really seen particularly in the **reduction of Stress** and the **increase in Empowerment** that the patient /carer felt as a result of using the artefact and being able to *recall their medical information*.

A.5 Evaluated Impact of the Check List

All participants agreed that using the check list in their medical appointments facilitated their ability to recall clinical information in their appointments. As we shall see this recall ability resulted in a number of further benefits for the CF patients and carers.

A.5.1 Improved Memory Recall

Two out of eighteen of our participants stated that as a result of the check list they had avoided a revisit to the doctor, as they had not left out any important symptoms when they went to their appointment. Others in the group supported this but felt that over the course of the 6 months they could not say that they had definitely saved on a revisit to the doctor. In comparison, sixteen of our participants said that as a result of using the check list they had raised matters that were a cause of concern with their doctor. All eighteen participants agreed that waiting to get in front of their doctor again to ask about something that was really worrying them about their own or their child's health was a huge strain to bear and that preventing such a situation from arising in the first place by using the check list was a real benefit in terms of reducing this potential stress.

A.5.2 Reduced Stress

Stress was a particular concern for our participants which was deemed by all eighteen to be augmented by their inability to remember their medical data. When asked "*Did using the check list help reduce your stress levels?*" all eighteen said that it had, with thirteen rating this at 4 or greater on a Likert scale of 1-5 (where 1

- it had little effect on their stress levels, and 5 it made a big difference to stress levels). Table A-5 augments our understanding of the impact that the check list has on the perceived stress levels of our CF patients and carers. One mother elicited a very stressful afternoon that she experienced whilst in a doctor's appointment with her sick CF baby. She said that the check lists coloured sections really helped her to refocus on the appointment whenever she became distracted by the child (who was quite distressed and agitated at the time due to an infection) - see her comment in Table A-5 (in bold).

Table A-5 Check List Stress Impacts

Impact Type	Participant Type	Example of quotes
Reduced Stress	Carer	*"The Check List may seem a small thing for some, but for me it was huge, I was so worried about my little girl, anything that helps reduce that stress is amazing. I don't think people should really judge unless they have walked in my shoes"*
Reduced Stress	Carer	***"With the Check List for the first time I could really hear what the doctor was saying to me**" (Mother of a CF child)*
Reduced Stress	Patient	*"As a CF patient it's not easy, when I am at the appointment, I feel my heart racing, I am stressed about what the doctor might say about my CF. The Check List won't take all the stress away, but it sure does help a lot. More than I thought it would to be honest. It's amazing what a bit of paper can do"*

A.5.3 Increased Empowerment

Health care is currently experiencing a paradigmatic change in the way patients are shifting from being submissive recipients to more independent, dynamic, and engaged participants (Snyder, 2016). Identified by the World Health Organization

as an eminent priority subject matter to be pursued globally (Delnoij et al., 2013), patient empowerment, referring to the set of self-determined actions based on patients' specific requirements for developing self-determination and expertise with their disease, has gradually become a key feature of a patient-centred approach to healthcare (Prigge et al., 2015). With regard to empowerment, the researchers sought to answer the question: "*Did using the check list give you a greater sense of empowerment?*" Again, all eighteen participants answered yes, albeit to varying degrees. Interestingly fifteen participants gave a 4 or 5 when asked to rate the check list on a Likert scale of 1-5 (where 1, it made very little difference to their sense of empowerment, and 5 it made a big difference to their sense of empowerment). These findings are again reinforced by the comments in Table A-6.

Table A-6 Check List Empowerment Impacts

Impact Type	Participant Type	Example of quotes
Empowerment	Patient	*"I feel at long last that I have a real voice in the what happens with my body. Before I felt voiceless, unheard, not comfortable speaking about my concerns. Now I have the courage to speak my mind. I can't believe how good it feels"*
Empowerment	Patient	*"The doctor assumes that the treatment he recommends is ok with me, he never really asks me. But now when I come with the check list, he knows I mean business, that I am serious about my CF, that I want to be heard, I want to have my say. I think it has really helped our relationship"*

A.6 Conclusion

In conclusion, the lead author (a 46 years old CF patient) has used Design Science Research to investigate the memory recall problems that CF patients and carers have regarding their medical information in a routine doctor's appointment. An artefact in the form of a check list has been designed, built, and evaluated. Not only has the artefact augmented the understanding of memory recall *within* a medical appointment, it has also resulted in an artefact with important key benefits: improving the ability to recall key clinical data, reducing stress and increasing empowerment for CF patients and carers. However, we have also seen that there are still issues with this paper-based artefact that need to be explored, understood, and resolved. Some outstanding questions include: How should we gain insights from all the data collected? How should we collect data between appointments?

This study has a number of limitations. The sample size is limited. Consequently, some of our qualitative findings demonstrated a strong trend but we would not claim that these results are statistically significant. We were the designers of the check list and its evaluation, introducing the possibility of observer bias. To reduce the effect of this bias, interviews were conducted with consistent objective data collection tools in the form of an externally vetted questionnaire that was designed not to lead the participant. Furthermore, the key benefits illustrated by comments in Tables A-5 and A-6 above speak for themselves and leave little room for misinterpretation. Finally, the presence of a Hawthorne effect, namely that the robustness of the check list was affected by the fact that the participants knew that they would be interviewed after each iteration and hence may have been more likely

to use the check list. But the longitudinal use of the check list by CF patients and carers is intended to counterbalance this.

We have shown in our study how beneficial pretotyping is as a means to gauge initial user appeal and behaviour prior to the possible creation of any digital innovations. Unfortunately, in today's world there is real tendency to run to a digital solution before really understanding a problem *within* its unique environment, or indeed before understanding the behaviours of the people for whom the solution is designed for. This all too often results in patients being expected to shoehorn into creations which are not fit for purpose, their particular disease or the actual environment they find themselves in.

From a practical perspective, as the check list has been designed by CF patients/carers and clinicians for CF patients/carers this facilitates real specific CF-related data recollection *before* and *during* a medical appointment. Which in turn improves memory recall, an essential ingredient for the CF patient or carer to ensure the successful outcome of their medical appointments. The check list also helps CF research as it contributes to CF patients and carer's wellbeing and outcomes as the evaluations conducted have shown.

From an academic perspective, the check list artefact is a new (in terms of structure, design and usage context) discursive template that facilitates a new patient led approach to tackling the problem of memory recall (from a patients/carers perspective) *during* and *after* medical appointments. This is invaluable as hitherto, no such tool existed for CF patients and carers to facilitate the act of remembering *within* a clinical encounter. Any research on memory (in clinical settings) seems to

be conducted primarily by clinicians and to date we have not encountered any research conducted by an actual CF patient (or other patient type) who is actually living with the problem to be solved. The research therefore highlights the enriching insights and contributions to knowledge that both patients and carers can make to the health innovation arena.

A.7 References

Ackermann S., Ghanim L., Heierle A., Hertwig R., Langewitz W., Mata R. & Bingisser R. (2016) Information structuring improves recall of emergency discharge information: a randomized clinical trial, Psychology, *Health & Medicine*, 22:6, 646-662.

Adams FM, Osgood CE. (1973) A cross-cultural study of the affective meaning of color. J Cross *Cult Psychol*. 4(2):135–156.

Arriaga A., Bader M., Wong J., Lipsitz S., Berry W., Ziewacz J., Hepner D., Boorman D., Pozner C., Smink D., Gawande A. (2013). Simulation-Based Trial of Surgical-Crisis Checklists. *N Engl J Med.* 368:246-253.

Baker, D. W., Parker, R. M., Williams, M. V., Pitkin, K., Parikh, N. S., Coates, W., & Imara, M. (1996). Th e health care experience of patients with low literacy. Archives of Family Medicine, 5 (6), 329–334.

Baddeley A. (2007) *Working Memory in Thought and Action*. Oxford, UK: Oxford University Press.

Besier T, Born A, Henrich G, Hinz A, Quittner AL, Goldbeck L. (2011) Anxiety, depression, and life satisfaction in parents caring for children with cystic fibrosis. *Pediatr Pulmonol*. 46(7):672-682.

Bickley L, (2013) *Bates Guide to Physical Examination and History Taking.* 11th Edition. Published by Wolter Kluwer `Lippincott Williams & Wilkins.

Borchard et al., (2012) A Systematic Review of the Effectiveness, Compliance, and Critical Factors for Implementation of Safety Checklists in Surgery. *Annals of Surgery* _ Volume 256, Number 6.

Chen Z, Cowan N. (2005) Chunk limits and length limits in immediate recall: a reconciliation. *J Exp Psychol Learn Mem Cogn* 31:1235–49.

Chin J., Madison A., Gao X., Graumlich J., Conner-Garcia T., Murray M., Stine-Morrow E., Morrow D. (2017) Cognition and Health Literacy in Older Adults' Recall of Self-Care Information. *Gerontologist*, Vol. 57, No. 2, 268.

Cohen, G. and Java, R. (1995), Memory for medical history: Accuracy of recall. *Appl. Cognit. Psychol*., 9: 273-288.

Deffenbacher, K. A., Bornstein, B. H., Penrod, S. D., & McGorty, E. K. (2004). A meta-analytic review of the effects of high stress on eyewitness memory. *Law and Human Behavior*, 28, 687–706.

Delnoij, D., & Hafner, V. (2013). *Exploring patient participation in reducing health care related safety risks.* World Health Organization.

Dzulkifli M., Mustafar M. (2013) The Influence of Colour on Memory Performance: A Review. *Malays J Med Sci*. 20(2): 3-9.

Elliot A., Fairchild M., Franklin A. (2015) *Handbook of color psychology* Cambridge University Press.

Epstein, W. (1967). Some conditions of the influence of syntactical structure on learning: Grammatical transformation, learning instructions, and 'chunking'. *Journal of Verbal Learning and Verbal Behavior*, 6, 415–419.

Eysenck MW. (2009) *Fundamental of psychology*. London (UK): Psychology Press.

Farley FH, Grant AP. (1976) Arousal and cognition: Memory for color versus black and white multimedia presentation. *J Psychol*. 94(1):147–150.

Gillespie, R., Florin, D., & Gillam, S. (2002). Changing relationships: findings of the patient involvement project. Retrieved from: www.kingsfund.org.uk

Gobet F, Lane PC, Croker S, Cheng PC, Jones G, Oliver I, et al. (2001) Chunking mechanisms in human learning. Trends *Cogn Sci*. 5:236–43.

Hall RH, Hanna P. (2004) The impact of web text-background color combination on readability, retention, aesthetics and behavioural intention. *Behav Inform*. 23(3);183–195.

Hannafin, R. D. (2004). Achievement differences in structured versus unstructured instructional geometry programs. *Educational Technology Research and Development*, 52, 19–32.

Haynes AB, Weiser TG, Berry WR. (2009) A surgical safety checklist to reduce morbidity and mortality in a global population. *New Engl J Med*. 360:491-9.

Hevner, March, Park and Ram (2004), 'Design Science in Information Systems Research', *MIS Quarterly* Vol. 28 No. 1, pp. 75-105.

Hess TM, Tate CS. (1991) Adult age differences in explanations and memory for behavioural information. *Psychol Aging* 1991; 6:86–92.

Hibbard, J. H., & Greene, J. (2013). What the evidence shows about patient activation: Better health outcomes and care experiences; fewer data on costs. Health Affairs, 32(2), 207–214.

Kaya N, Epps HH. (2004) *Proceeding of Interim Meeting of The International Color Association*, AIC 2004 Colors and Paints. Colour-emotion association: Past experience and personal preference.

Kessel RPC. (2003) Patients' memory for medical information. *J R Soc Med* 96:219–22.

Kvedar, J. C., Colman, C., and Cella, G. (2015). *The Internet of Healthy Things*. Boston (MA): Partners Connected Health.

Langewitz W., Ackermann S., Heierle A., Hertwig R., Ghanim L., Bingisser R. (2015) Improving patient recall of information: Harnessing the power of structure Wolf. *Patient Education and Counseling* 98 716–721.

Leape L., (2014). The Checklist Conundrum, *N Engl J Med*. 13;370(11):1063-4.

Ley, P. (1979). Memory for medical information. *British Journal of Social and Clinical Psychology*, 18, 245–255.

Li G, Ning N, Ramanathan K, He W, Pan L, Shi L. (2013) Behind the magical numbers: hierarchical chunking and the human working memory capacity. *Int J Neural Syst* 23:1350019.

Martin L., Dimatteo M., (2014) *The Oxford Handbook of Health Communication, Behaviour Change, and Treatment Adherence*. Oxford University Press.

McPherson, M. L., Smith, S. W., Powers, A., & Zuckerman, I. H. (2008). Association between diabetes patients' knowledge about medications and their blood glucose control. *Research in Social and Administrative Pharmacy*,.4, 37–45.

Mead, N., Bower, P., & Roland, M. (2008). Factors associated with enablement in general practice: Cross-sectional study using routinely-collected data. British Journal of General Practice, 58(550), 346–352.

Miller, G. A. (1956). The magical number 7, plus or minus 2 – Some limits on our capacity for processing information. *Psychological Review*, 63, 81–97.

Norman D. (2013) *The design of everyday things*. MIT press.

Ong, L. M., de Haes, J. C., Hoos, A. M., & Lammes, F. B. (1995). Doctor–patient communication: A review of the literature. *Social Science & Medicine*, 40, 903–918.

Pan Y. (2012) Attentional capture by working memory contents. *Can J Exp Psychol*. 64(2):124–128.

Parikh, N. S., Parker, R. M., Nurss, J. R., Baker, D. W., & Williams, M. V. (1996). Shame and health literacy: the unspoken connection. Patient Education & Counseling, 27 (1), 33–39.

Peffers, Tuunanen, Rothenberger and Chatterjee (2007), 'A Design Science Research Methodology for Information Systems Research', *Journal of Management Information Systems* Vol. 24, No. 3, pp.45-77.

Personal Injuries Ireland (2017) *Medical Negligence in hospitals in Ireland.* http://www.personalinjuryireland.ie/medical-negligence-in-hospitals-in-ireland/ (Last accessed online 26/11/2017).

Prigge, J., Dietz, B., Homburg, C., Hoyer, W., Burton, J. (2015) Patient empowerment: A cross disease exploration of antecedents and consequences. *Intern. J. of Research in Marketing* 32, 375–386.

Ratjen, F., Bell. S.C., Rowe, S.M., Goss, C.H., Quittner, A.L., Bush, (2015) Cystic fibrosis. *Nature Reviews Disease Primers*. 1:15010.

Rosen M., Pronovost P., (2014) Advancing the Use of Checklists for Evaluating Performance in Health Care. *Academic Medicine*, Vol. 89, No. 7.

Safeer, R. S., & Keenan, J. (2005). Health literacy: The gap between physicians and patients. *American Family Physician*, 72, 463–468.

Sarkar, U., Schillinger D., Bibbins-Domingo K., Nápoles A., Karliner L., Pérez-Stable E., (2011) Patient–physicians' information exchange in outpatient cardiac care: Time for a heart to heart? *Patient Education and Counseling*, Volume 85, Issue 2, Pages 173-179.

Savoia A. (2011). *Pretotype It*, 2nd Ed. www.pretotyping.org/uploads/1/4/0/9/14099067/pretotype_it_2nd_pretotype_edition-2.pdf [Last accessed 14/11/2017].

Schraa J., Dirks J., (1982) Improving patient recall and the comprehension of the treatment regime. *Journal of Asthma*, 19(3), 159162.

Schwesinger, B., (2010). The Form Book, Best Practice in Creating Forms for printed and online use. Thames & Hudson.

Shapiro, D. E., Boggs, S. R., Melamed, B. G., & Graham-Pole, J. (1992). The effect of varied physician affect on recall, anxiety, and perceptions in women at risk for breast cancer: *An analogue study. Health Psychology*, 11, 61–66.

Simmons M., Chew I., (2015) *How to Create A Checklist* http://www.beseminal.com/wpcontent/uploads/2015/11/HowToCreateAChecklistFinal.pdf [Site Last visited 21/11/2017].

Snyder H., J. Engstro¨m J., (2016) The antecedents, forms and consequences of patient involvement: A narrative review of the literature / *International Journal of Nursing Studies* 53 351–378352.

Sternberg RJ. (2009) *Cognitive Psychology*. 5th Ed. Belmont (BE): Wadsworth Cengage Learning.

Stock C., Sundt T. (2015) Timeout for Checklists? *Annals of Surgery*. Volume 261, Number 5.

Traupmann, K. L. (1975). Effects of categorization and imagery on recognition and recall by process and reactive schizophrenics. *Journal of Abnormal Psychology*, 84, 307–314.

Twomey M. (2015) Blueprint - Cloud Strategy Diploma, The Irish Management Institute. Unpublished.

White CS, Mason AC, Feehan M, et al. (1995) Informed consent for percutaneous lung biopsy: comparison of two consent protocols based on patient recall after the procedure. *AJR Am J Roentgenol* 165:1139e42.

Wichmann FA, Sharpe LT, Gegenfurtner KR. (2002) The contributions of color to recognition memory for natural scenes. *J Exp Psychol Learn*. 28(3):509–520.

World Alliance for Patient Safety. (2008) WHO surgical safety checklist and implementation manual. Available from: http://www.who.int/patientsafety/safesurgery/ss_checklist/en/index.html.

World Health Organisation. (2010) *New scientific evidence supports WHO findings: a surgical safety checklist could save hundreds of thousands of lives*, Available from: http://www.who.int/patientsafety/safesurgery/checklist_saves_lives/en/.

Yohannes AM, Willgoss TG, Fatoye FA, Dip MD, Webb K. (2012) Relationship between anxiety, depression, and quality of life in adult patients with cystic fibrosis. *Respir Care* 57(4):550-556.

Appendix B

Paper 2: Information Retrieval within the Medical Appointment: A Review of the Literature

B.1 Abstract

Purpose: – Information retrieval/memory recall by patients/carers *within* the medical appointment is reported to be of paramount importance to the outcome of the medical encounter. The rationale behind this paper is to delve into the current literature to ascertain the pervasiveness of long-term information retrieval/memory recall concepts *within* this intricate environment, including the disease states in which patient information retrieval/memory recall research has been conducted, affording an analysis of research activities in order to identify the gaps in knowledge that currently exist.

Design/methodology/approach: – A wide-ranging literature review was carried out in pursuance of the current state of knowledge. A rigorous systematic process detected 49 papers that clearly consider information retrieval/memory recall events *within* the medical appointment. Content analysis was conducted using Webster and Watson's (2002) Concept-Centric Matrix in conjunction with open coding techniques, giving rise to the detection of 227 concepts, which were subsequently assembled into 63 categories. A critical examination of the data characterised the trends and apertures in the literature.

Findings: – Our analysis reveals the prevalence of long-term information retrieval/memory recall concepts, and the disease states that have conducted patient information retrieval/memory recall research (*within* the medical appointment) reported in writings over the past 43 years. Additionally, the review advances our comprehension of memory recall *within* the medical appointment via a model of the *elicitation* phase of the medical appointment. This model and the exploration conducted draws our attention to a variety of gaps in research, serving as suggestions for future potential enquiry.

Research implications: – This paper is of significance to the IS, medical communities, and patients/carers, as it facilitates an augmented appreciation/understanding of information retrieval/memory recall (and the importance of same to the diagnostic/decision-making process and on patient's safety and health), *within* the intricate setting of the medical appointment. Moreover, it highlights the requirement for further consideration/attention to memory recall/information retrieval *within* the medical encounter. Additionally, the conceptual model of memory recall/information retrieval in the *elicitation* phase of the medical appointment facilitates our comprehension and shared understanding of the *elicitation* phase *within* this complex environment, whilst also serving to provoke a number of questions/research opportunities.

Keywords – Information retrieval, Memory recall, Patient, Medical, Appointment.

B.2 Introduction

Memory or remembering is something we often hear people grumble about, apologise for, laugh about, and continually struggle with as we go about our daily lives. Yet few of us would go so far as to describe ourselves as "*stupid*" because we have memory lapses. Indeed, human society accepts as normal that we (often despite our best efforts) will on occasion forget; we fail to recall people's names, fail to remember appointments, sometimes we even fail to remember very important dates such as a person's birthdays or anniversaries. Schacter (2001) refers to the seven sins of memory (Table B-1), acknowledging that these sins are part of what make us human, and are the indispensable consequences of the intrinsic worth that bring about such rich and malleable memories.

At a rudimentary level, human memory is the mental capacity that grants individuals to preserve the occurrences that they experience on a daily basis, and to later recall them in some way, where the prevailing modern representation for memory is the computer metaphor (Radvansky, 2017). And while "*our memories might be less reliable than those of the average computer… they are just as capacious, much more flexible, and a good deal more user friendly"* (Baddeley et al., 2015, p.22).

Table B-1 The Seven Sins of Memory (adapted from Schacter, 2001)

Sin	Description
Transience	Memories for facts and events are forgotten over time. First reflected in the "*forgetting curve*" by Ebbinghaus (1885).
Absent-Mindedness	Absent-mindedness happens when information is not encoded correctly when information is first presented due to attention been focused elsewhere.
Blocking	When people have difficulty retrieving a desired memory because other memories are obstructing access.
Misattribution	Misattribution occurs when one can remember something but misattribute to an incorrect time, place or person.
Suggestibility	Suggestibility occurs when new/altered memories are provided by outside sources, possibly causing correct information to be forgotten or distorted.
Bias	Bias can occur when memories are altered by what one already knows, believes or expects. Memories can also be changed by one's current mood and emotional state.
Persistence	Persistence in memory is compromised by knowledge that should be forgotten or information that one would prefer to forget.

Considered by Radvansky (2017) as perhaps one of the most fundamental features of hominid cognition, memory facilitates the very structure we seek in our lives, it makes us who we are, bestowing us with a sense of individuality. It is one of the most private elements of ourselves and is vital to the construction of the societal attachments amongst human beings, where we endeavour to interchange memories, frequently imparting extracts from our lives by way of narratives/tales (Ibid).

Within the byzantine environment of the medical appointment, these histories are an integral ingredient of a medical diagnosis, and are often contingent on a patient's or carers capacity to remember information correctly, and so are a key component to the success of the medical appointment and to the health outcomes of the patient (Cohen et al., 1995).

This paper aims to contribute to the Information Systems (IS) and Medical communities by augmenting our understanding of the role that long-term memory and information retrieval/memory recall has *within* the medical appointment, specifically the *elicitation* phase. The paper examines the progress of research in this area, identifying the gaps in the extant literature and making recommendations for future research. This investigation is undertaken as it is essential to have a comprehensive understanding of information retrieval/memory recall *within* the medical appointment, its components, and the critical contribution that a thorough understanding of information retrieval/memory recall can make to an appointment's success.

This paper is arranged as follows: Section B.3 presents a brief overview of the medical appointment, memory, memory *within* this context and concludes with the research question to be considered in this study; Section B.4 describes the research method used in performing the literature review, including the journal selection strategy and the data analysis techniques used; Section B.5 explains the examination conducted in our enquiry and the findings of our investigation of information retrieval/memory recall *within* the *elicitation* phase of the medical appointment. We bring our study to a close by summarizing our exploration,

presenting our conceptual model, making recommendations for future investigations, and addressing the limitations of the review.

B.3 Background

B.3.1 The Medical Appointment

In recent times there has been a dramatic increase in research pertaining to the medical appointment by the health community, wherein they have come to realise "*the complexity and importance of the medical interview, particularly as it influences communication effectiveness, data accuracy, clinical decision-making, ethical decision-making, compliance, patient satisfaction, clinician satisfaction, and clinical outcome"* (Lazare, 1995, p.3). From a communications standpoint this doctor patient/carer encounter could be described as an account or canonical linguistic structure that stipulates a chain of actions and the connections between them (Radvansky, 2017). "*The most commonly acknowledged function of the medical interview is to determine the nature of the problem, or to make the diagnosis*" (Lazare, 1995, p.4). The patient's narrative is crucial for diagnosis, but also for the clinician's understanding of what the diagnosis means for the patient and how it affects the patient's life. The latter is essential in a person-centred approach and for recommending a suitable intervention/treatment.

In pursuance of a diagnosis, the clinician participates in a bi-directional exchange (*within* the medical appointment – called the *elicitation* phase – Figure B-1) with the patient/carer vis-à-vis their medical history, current medication, current well-being and so on (Sarkar et al., 2011). The importance of the diagnosis was first

documented by the Canadian doctor William Osler, who directed his students to '*listen to your patient, he is telling you the diagnosis*', highlighting the central role of the patient's narrative (Gandhi, 2014; Osler, 1914). And so, '*Taking a medical history'* came to be a crucial aspect of clinical reasoning in ascertaining the cause of an illness (Cushing, 2016), as "*without a sound grasp of what is going on, interventions cannot be meaningful or effective*" (Probst, 2015, p.13).

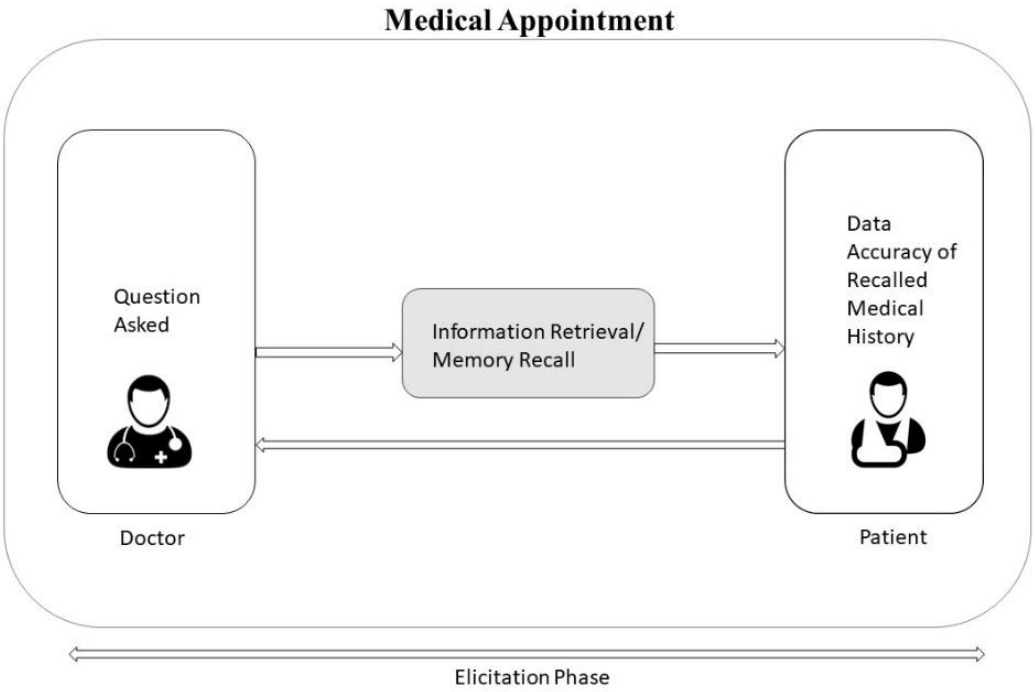


Figure B-1 Elicitation phase of the medical appointment

Research confirms that a patient's medical history provides in the region of 60-80 percent of the data required for diagnosis to be formulated (Hampton et al., 1975; Sandler, 1980; Kassirer, 1983). In cases where a medical diagnosis has already been made (for instance with chronic patients), the appointments purpose turns into observation, where the doctor monitors the patient's illness and disease activity (Lazare, 1995).

Owing to the importance of the diagnosis doctor-patient/carer narratives must be clear and understandable, moving beyond a mere sequence of events, to deliver a comprehensive scaffold for understanding "*how and why"* incidents developed as they did, whereby the framework consist of plans, impetuses, deliberations, and emotions that captures the unique human texture and setting for each occasion (Chafe, 1990; Labov, 1982; Linde, 1993), where each patient is*" understood as a unique human being*' (Balint, 1961, p.40). Therefore, the doctor must also figure out the patient's response to his or her illness (which is often temporal in nature) including the patient's self-efficacy regarding their disease management (Lazare 1995), and then make available suitable information to the patient/carer *within* the *elucidation*/*explanatory* phase of the appointment (Martin et al., 2014). Here the doctor endeavours to inform the patient/carer apropos their diagnosis, alterations to medication regimes, self-management strategies, or advice about additional diagnostic procedures (Ibid).

B.3.2 Memory

Before embarking on our exploration of the literature on information retrieval/memory recall *within* the medical appointment this section provides the reader with a very brief background on seminal works in the area of human memory. As a heuristic guide for understanding how memory works Atkinson and Shiffrin (1968) proposed one of the first models of memory; The Modal Model (Figure B-2) which endures as a guide to the topic of memory. Their model is not a single entity but comprised of a memory system with 3 different constituents: sensory registers (visual, auditory or haptic), short-term memory (STM) and long-

term memory (LTM) that have evolved over time to deal with various pressures and activities (Klein et al., 2002; Sherry & Schacter, 1987).

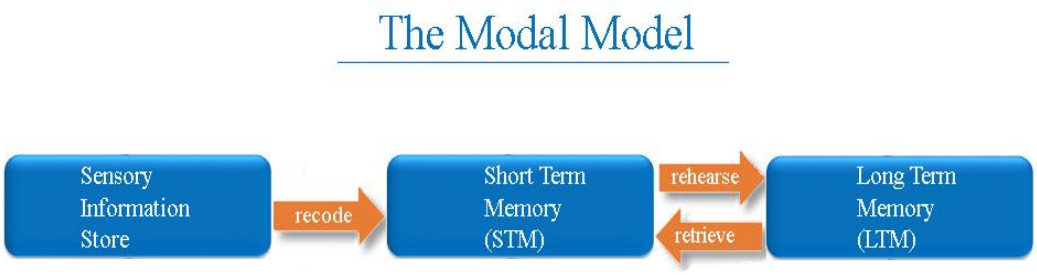


Figure B-2 Atkinson and Shiffrin - Modal Model

As the retrieval of information from LTM *within* the medical appointment is of particular interest to our exploration, the next model we visit is Tulving's (1985) triarchic theory of memory (Figure B-3). LTM is divided into two classes: nondeclarative and declarative memory, indicating the diverse tasks required of memory, as well as various levels of control and conscious awareness (Radvansky, 2017).

Nondeclarative memory (often referred to as Procedural memory) is an old system that has evolved over time and is described as a-noetic (a: "*no*"; -noetic: "*thinking*") in Tulving's (1972) system because it does not require conscious awareness, and pertains to memories that are not easy for a person to articulate, but that still effect our lives (Ibid). It is defined by Schacter (1987) as implicit memory as the person is not aware that their memory is being used, such as when one cycles a bike.

Declarative memory on the other hand refers to memories that are easy for a person to express and talk about, and is described by Schacter (1987) as explicit memory, as the person is actively and consciously trying to remember something, such as

remembering the date a particular symptom started. This is the aspect of LTM that we will focus upon *within* the confines of the medical appointment.

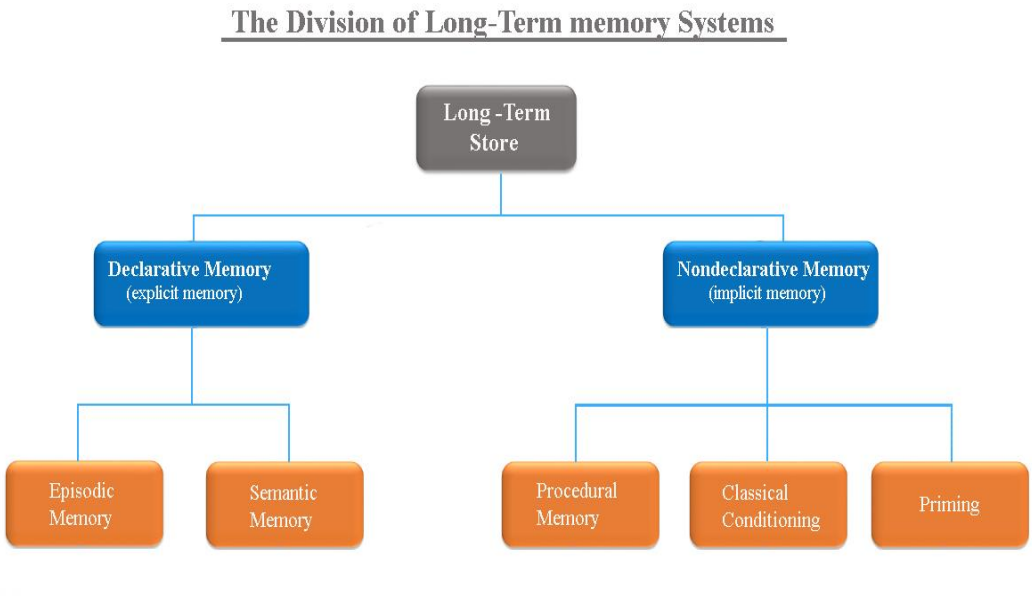


Figure B-3 Tulving's Triarchic Theory of Memory (Squire, 1986)

B.3.3 Information retrieval/memory recall *within* the medical appointment

When patients/carers attend medical appointment, they are expected/assumed to be proficient in several aspects of information utilisation, including communicating information correctly and retaining information accurately, for use at a later date. While both areas are problematic for the patients/carer (and hence the doctor), research has to date been primarily directed on how proficiently patients/carers recall what the doctor has said to them (*within* the course of the *elucidation/explanatory* phase of the appointment), and how this may be improved upon (e.g., Ley et al., 1973; Bradshaw et al., 1975). At first glance this is very understandable as studies show that on average patients/carers fail to recall

approximately half of the information imparted to them *within* medical consultations (Kessels, 2003), and that doctors often overestimate the ability of patients/carers to remember information (Langewitz et al., 2015). It is, of course important that such research is conducted as it directly impacts on adherence and patient outcomes (Martin et al., 2014).

However, as pointed out by Cohen et al. (1995), the patients/carers ability to remember and communicate medical history (*during* the *elicitation* phase of the medical appointment) together with any health-related occurrences that have occurred outside the medical appointment (such as illnesses, symptoms, injuries, visits to other health professionals, treatments/medications, etc) has received far less consideration (Cohen et al., 1995). This despite the fact that such data is fundamental to the diagnostic/decision-making process that a doctor endeavours to perform *within* the medical appointment (Ibid). Indeed, research has revealed how "flawed, incomplete and erroneous" (Cohen et al., 1995. p.273) memory recall of medical history is *within* the medical appointment. In fact, as the amount of data to be remembered increases, the portion of information that is accurately recalled actually diminishes significantly (McGuire, 1996). To further underscore how memory recall/information retrieval manifests itself *within* the medical appointment we again take Schacter's Seven Sins of Memory (Table B-2), but in this instance we give examples of each as they may be exhibited *within* the context of the medical appointment. As we can see, there are a variety of memory recall/information retrieval errors that can arise, directly impacting on the quality of the information imparted to the doctor, hindering the diagnostic process.

Table B-2 The Seven Sins of Memory as they may manifest within a medical appointment

Sin	Example
Transience	Forgetting a medical event that happened weeks ago.
Absent-Mindedness	When attention is focussed on a sick child (in an appointment) rather than the treatments details that the doctor is explaining. This results in a failure to recall treatment instruction correctly, which may in turn affect adherence
Blocking	For example, a carer may be trying to think of a particular medication name, but another, similar medication keeps appearing in the carers mind.
Misattribution	One may recall a particular medical event, but the time or place where the symptom occurred is reported erroneously.
Suggestibility	This may happen if a patient/carer is inclined to accept and act on the suggestions of others, altering their memory of a past event.
Bias	For example, recollection of ones past health can often be influenced by ones current health status.
Persistence	For example a traumatic health event that a patient/carer would prefer to forget, but cannot.

Perhaps unsurprisingly, 56% of diagnostic errors *within* the medical appointment are brought about by poor medical history (WHO, 2016), such as deficient and imprecise information recalled by the patient (Berner & Graber, 2008). Such poor-quality information can have a number of insidious consequences (Redman, 2016), where misdiagnosis and poor decisions regularly give rise to patients being exposed to unnecessary costly medical procedures, often producing avoidable pain and

distress (Personal Injury Team Ireland, 2017). Furthermore, a misdiagnosis may result in a worsening of a patient's illness, (leading to life-changing outcomes), considerable psychological suffering/issues and in certain situations death (Ibid).

Therefore, as an alternative to a myopic view of information retrieval/memory recall (where we only consider recall of information imparted to patients/carers by their doctor/s), it becomes obvious that we should/must now broaden our appreciation of information retrieval/memory recall *within* the context of the medical appointment to also include the *elicitation* phase of the encounter, focusing a spotlight on the overlooked health-related events that ensue between appointments. These health-related episodes are also essential components or fragments of the jigsaw that is a patient's medical history, and must take into account frequencies, dates, durations and severities of symptoms, providing the very specifics that a doctor requires to piece together an accurate diagnosis, and subsequently recommend appropriate treatments to a patient/carer (Cohen et al., 1995).

As one may well appreciate the use of memory by a patient/carer is continuous and yet wide-ranging with regards to time, location and context in the course of dealing with an illness. It is, of course, entirely possible to picture a patient/carer retrieving information from memory *before, after and between* their medical appointments, however the aim of this investigation is to discover, understand, categorize and synthesize the extant literature that clearly remarks on information retrieval/memory recall *within* the context of the *elicitation* phase of the medical appointment. Probing the viewpoints/approaches that are reported in academic

journal publications, with a view to augmenting our grasp of memory recall, and specifically its function *within* the medical appointment. In particular we sought to answer the following research question:

RQ. *What long term information retrieval/memory recall concepts have been reported within the context of the medical appointment, and in what medical areas/conditions have they been reported?*

As a result of being able to answer this question we will be able to identify the gaps that exist in the current literature regarding information retrieval/memory recall *within* the *elicitation* phase of the medical appointment? As one may envisage this research holds different significance for the various stakeholders *within* this environment, which we will also examine.

B.4 Method

Creating a clear and rigorous protocol in advance of conducting a review of literature is one of Kitchenham and Charter's (2007) significant recommendations. This was particularly pertinent in this study, and so we turned to Webster and Watson (2002) conceptual model (the Concept-Centric Matrix - Table B-3) that "*synthesizes and extends existing research*" (Webster & Watson, 2002, p.14), as "*a coherent review emerges only from a coherent conceptual structuring of the topic itself*" (Webster & Watson, 2002, p.14), where concepts "*determine the organizing framework"* (Webster & Watson, 2002, p.16).

Table B-3 Webster & Watson's Concept Centric Matrix (2002)

Source/Papers	Concepts			
	Concept 1	Concept 2	Concept 3	Concept 4
1		X		
2	X		X	
3		X	X	
4			X	

Our exploration also implemented eight coding steps (Finney and Corbett, 2007; Carley, 1993; Alhassan, 2016) in order to conduct the content analysis on a selection of journal publications. These stages encompass data gathering and coding measures which assist the researcher in achieving clarity and precision in their methodology. These stages, and the decisions reached, are expanded upon below.

Stage 1: Decide the level of analysis

Webster and Watson (2002, p.16) advise that as "*IS is an interdisciplinary field straddling other disciplines, you often must look not only within the IS discipline when reviewing and developing theory but also outside the field".* And so, in order to advance the depth and breadth of our research niche, our journal selection was undertaken with careful consideration, ensuring we had as wide a representation of research as possible across all relevant disciplines, and not confining ourselves solely to the area of IS. It was imperative to conduct the search in this way to assure as holistic a view as possible (Helmericks et al., 1991). A total of 39 databases (Appendix M) in the areas of IS, medicine, and psychology were searched in February 2018 (and again in August 2018 to check for any new articles) using the

keywords of "*information retrieval/memory recall*", "*patient*", "*medical*" and "*appointment*" in either the title or abstract. It was important to ensure that the selected databases covered all the major journals within each discipline, for instance in the medical area the databases chosen were PubMed, CINAHL Plus, Embase, Cochrane Library, BMJ, and Medline.

In this step we decided on the level of analysis that is required in the review; the degree of exploration in this investigation took the entire journal paper into consideration in order to achieve as comprehensive an understanding of information retrieval/memory recall *within* the medical appointment setting as possible. With this in mind we set about gathering the papers for our literature review as outlined in the flowchart in Figure B-4.

The overall data collection resulted in a total of 1,811 English language publications. Each journal review started with the title, table of contents, and extended to the abstracts and keywords. This was done in order to allow us to identify publications that could be excluded or included. Of the 1,811 publications, 1,395 were excluded as they focused on human memory disorders (our research focus was on the general/chronic patient population, but not those with cognitive memory disorders). A further 367 were excluded as they had been published to serve a separate area of study that was not related to the information retrieval/memory recall of patients *within* the medical appointment. At the end of the exclusion/inclusion phase of our study we were left with 49 papers for the review (Appendix N).

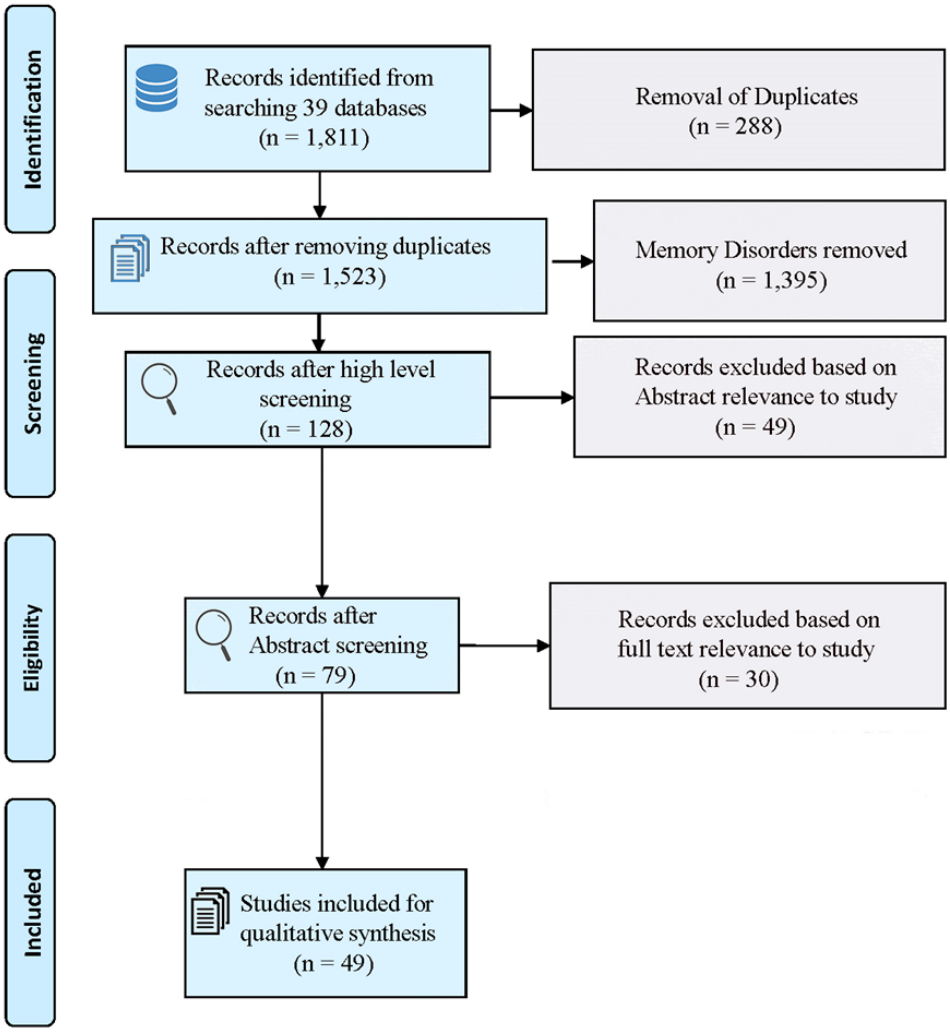


Figure B-4 Review of Literature Flowchart (adapted from Zhou, 2015)

Stage 2: Decide how many concepts to code for

In this phase researchers decide on whether to code text using predefined concepts or develop a list of concepts as they emerge during the coding process (Finney & Corbet, 2007; Alhassan et al., 2016). In stage 2 we elected to use open coding to code for concepts relating to information retrieval/memory recall *within* the medical appointment. Open coding relates to the naming and labelling of occurrences

through careful inspection of text. The use of open coding for conducting content analysis of academic papers is extensive (for examples see Finney & Corbett, 2007; Goode & Gregor, 2009; Grahlmann et al., 2012). During open coding, the information is broken down into distinct parts, thoroughly scanned, compared for resemblances and variances, and questions are asked about the observables as revealed in the data (Strauss and Corbin, 1990). This transforming of lexical information from natural language texts into semantic patterns also allows researchers to catch sight of likely routes in which they may take their research. In tandem with this, they also become more selective and focused conceptually on the research question/s in a study.

Stage 3: Decide whether to code for the existence or frequency of a concept

We decided at the protocol stage to code for the frequency of concepts rather than just the existence of a concept. Coding for existence involves listing the concepts as they emerge with little else gained from the exercise in terms of insights. However, by expanding the process to consider the frequency of concepts it allows for the construction of a descriptive, multi-dimensional preliminary framework for subsequent analysis, thereby augmenting the insights gained from the exploration of the literature, making a conversation of saliency and emphasis conceivable (Finney & Corbett, 2007; Alhassan et al., 2016). One "*can gauge that your review is nearing completion when you are not finding new concepts in an article set*" (Webster & Watson, 2002, p.16).

Stage 4: Decide on how you will distinguish between the concepts

In short, this stage is referred to as the level of simplification of expressions where researchers decide to code for concepts precisely as they appear or if possible, in another revised or abstracted structure (Finney & Corbett, 2007; Alhassan et al., 2016). And so, in this study, any words that implied the same sense were classified under the same construct (a construct being an idea containing various conceptual elements) using open coding analysis practises (Corbin and Strauss, 1990). For instance, "*event memory*" and "*Episodic memory*" having similar connotations were placed within the same concept.

Stage 5: Develop rules for coding the text

Central to the entire discipline of coding is adhering to approved translation rules throughout the coding process, thus, ensuring consistency, and internal validity (Finney & Corbett, 2007; Alhassan et al., 2016). The following rules were developed and applied in the review protocol: All included papers were read for the first time and emphasis was placed on noting references to "*information retrieval/memory recall*". At this stage no categories had been determined. Similar concepts that emerged were then grouped in categories (see Appendix O for an example of the categorisation of medical area according to systems of the human body) where it was appropriate to do so. Each category was reconsidered, and concepts were scrutinized once more to ensure validity of coding.

Stage 6: Decide what to do with "irrelevant" information

In this stage we contemplated what actions were to be taken regarding any text that was not coded (Finney & Corbett, 2007; Alhassan et al., 2016). As this literature review embarked on understanding all aspects of information retrieval/memory recall *within* the medical appointment the content analysis included the entire document; however, we actually coded only those aspects of the text that clearly related to information retrieval/memory recall *within* this ecosystem. This is akin to Carley (1993) who suggested that deleting irrelevant information can facilitate content analysis procedures by generating simplified text and conceptual refinement. Therefore, the question of what to do with extraneous coded information did not become an issue.

Stage 7: Coding the text

Following stage 6 we conducted the actual coding process following all translation rules agreed upon in stage 5 (Finney and Corbett, 2007; Alhassan et al., 2016) and employing open coding analysis, which is "… *the process of breaking down, examining, comparing, conceptualising, and categorising data*" (Corbin and Strauss, 1990). The salient concepts and classifications identified arise from analysing the text of each paper through the use of open coding can be considered as emerging activities.

The open coding process aims to expose the concepts or key ideas that may be concealed within the text and are quite possibly related to a phenomenon of significance (Bhattacherjee, 2012), thereby facilitating the discovery of new

information from text, and may indeed "*assist in separating signals from noise*" (Watson, 2005, p.1233). Table B-4 defines the terms that are included in open coding pertinent to this review as outlined by Corbin and Strauss (1990).

We used two analytical techniques to accomplish open coding effectively (Corbin & Strauss, 1990; Glaser, 1992). Firstly the "*making of comparisons*" where each concept was examined for the parallels or distinctions that it may have when measured against other concepts. Concepts that were found to be conceptually similar were put together under higher order explanatory classifications (Corbin and Strauss, 2008).

It is only through constantly comparing "*incident to incident, incident to concept*" (Glaser, 1992, p. 39) and, "*concept to concept*" (Glaser, 1978, p. 50) that discoveries are made from such data analysis. The manner in which comparisons are made facilitates the differentiation of categories from each other and allows for the discovery of the properties and elements of each category (Corbin & Strauss, 2008; Glaser, 1992). The second practice used when coding the text involved "*asking questions*"; here we had to understand what was going on in the data analysis (Glaser, 1978), as we developed categories (Appendix O) and properties from emerging concepts (Glaser, 1992). Here we closely scrutinized our data in a line-by-line manner, compelling us to authenticate and saturate categories, thus moderating the chances that any noteworthy category was omitted (Glaser & Holton, 2004). Confirming a meticulously coding in stage 7 ensured that we were on the best footing possible going into stage 8.

Table B-4 Definitions of the terms that are used in open coding (adapted from Corbin & Strauss, 1990, p.61)

Term	Definition
Concept	Concepts are the elementary units of analysis- where incidents, events, or happenings that point towards potential signs of phenomena are given conceptual labels
Category	Concepts that relate to the same phenomenon may be assembled to develop categories. Categories are higher in level and more abstract than the concepts they correspond to.
Coding	Coding is the fundamental analytic process used by the researcher
Properties	Characteristics or features pertaining to a category

Stage 8: Analysing the results

After coding the data, we decided how to review and present our results (Finney & Corbett, 2007; Alhassan et al., 2016). In terms of presenting information retrieval/memory recall activities, the primary method used in the analysis stage involved reviewing the constructs in terms of frequency. However, to augment the level of investigation the frequency results were also scaled reflecting the levels of reporting. Here we created scale levels of: none (no mention of the concept), low (a concept is only touched upon in a paper) and high (a concept is a focus of a paper).

B.5 Analysis & findings

A number of Microsoft Excel spreadsheets were developed whilst reviewing the 49 selected papers as the before mentioned open coding analysis was applied iteratively (as per stage 7). As well as presenting a brief overview we sought to answer the following:

RQ. *What long term information retrieval/memory recall concepts have been reported within the context of the medical appointment, and in what medical areas/conditions have they been reported?*

B.5.1 Overview

The selection process produced a total of 49 articles engaged in information retrieval/memory recall research *within* the medical appointment for the period 1975 to 2018. An initial assessment of this collection of articles proves itself to be of interest and, hence, deserves some attention. Firstly, all 49 studies were classified and grouped according to journal type and publication date (Table B-5).

The results show that the majority of papers are predominantly in health/medical (27 papers) journals with an increase in publications in these journals over the last thirty-two years from three to 16 papers. This rise in research (of information retrieval/memory recall *within* the medical appointment) in health/medical journals is most likely due to the medical appointment becoming the focus of rigorous investigations due to its various complexities Lazare (1995). This trend is somewhat different however for Geriatric journals where one would expect a continual rising in paper number over time (due to the fact that older adults experience an increase

in age-related cognitive changes that often impede their ability to process and remember information (Brown & Park, 2003; Kessels, 2003); we actually see a decrease in the last decade following an initial increase from 1986 to 2007. This is remarkable given that in 2017 there were 962 million people in the world aged 60+, with this number set to rise by three percent per year, where by 2050 every nation in the world is estimated to have approx. 25 percent of its population in the 60+ age category (United Nations 2017).

Table B-5 Prevalence of paper per Journal type

Decade	1975-1985	1986-1996	1997-2007	2008-2018	
Journal Type					**Total**
Exercise Sport				(Labban et al., 2011)	**1**
Health Economics				(Holman et al., 2010)	**1**
Geriatric	(Crook et al., 1979);		(Belli et al., 1999); (Brown et al., 2002); (Bird et al., 2004); (Vance et al., 2007);	(Jansen et al., 2008); (Jones et al., 2015)	**7**
Behaviour/Psychology	(McKinlay et al., 1975); (Schank et al., 1980)	(Baddeley et al., 1988); (Huttenlocher et al., 1990); (Dinges et al., 1992)	(Albert et al. 1999); (Ball et al., 2001); (Albert et al., 2003); (Elzinga et al., 2005); (Matheis et al., 2007); (Jessen et al., 2007);	(Hoppe et al., 2008); (Amin et al., 2013)	**13**
Health/Medical		(Smith et al., 1993); (Homedes et al., 1994) ; (Grubb et al., 1996)	(Drysdale et al., 2000); (Grubb et al., 2000); (Rand et al., 2000); (Crews et al., 2001); (Keeble et al., 2002); (Hufford et al., 2003); (Rubin et al., 2003); (Smith-DiJulio et al., 2005);	(Ferguson et al., 2008); (Rennick et al., 2009); (Posma et al., 2009); (Kaufman et al., 2009); (Pressler et al., 2011); (McKinstry et al., 2011); (Grober et al., 2011); (Waldron et al., 2011); (Monajemi et al., 2011); (Redelmeier et al., 2012); (Misra, et al., 2013); (Hanon et al., 2014); (Meeusen et al., 2015); (Brick et al., 2016); (Ahn et al., 2017); (Lipson et al., 2018)	**27**

Behavioural/Psychological journals share this unusual trend from an initial raising trajectory to a decrease in the last decade. One possible explanation may be that research in information retrieval/memory recall *within* the medical appointment has

taken on a more medical-orientated focus (which previously may have had more of a geriatric/behavioural/psychological research emphasis), as it is now appreciated that *"forgetting"* is not just a geriatric/behavioural/psychological issue, it is a great deal more, it's an extremely complex area with significant impacts on patient diagnosis and outcomes (Martin et al., 2014).

What is also thought-provoking is the absence of papers within IS journals and the relatively low number of publications in other disciplines such as health economics and sport. One would expect the existence of publications in IS journals given the relationship between information retrieval/memory recall, and the supply and demand of accurate information *within* what is essentially a business encounter with its own unique variables. Nevertheless, given the seismic shift occurring in health, and with the advent of digital health, this trend will most likely change over the coming years.

Following the consideration of the prevalence of journal type, we classified each paper by research method used (Table B-6) and also conducted a citation analysis (Figure B-5). The classification identified 38 empirical studies and 11 conceptual (10 were literature review papers). This imbalance in research design may indicate the need for an increase in more conceptual methods and indeed the opportunity for theory building.

Table B-6 Research Design

Research Design			
Empirical			**Conceptual**
Quantitative	Qualitative	Mixed	11
17	11	10	

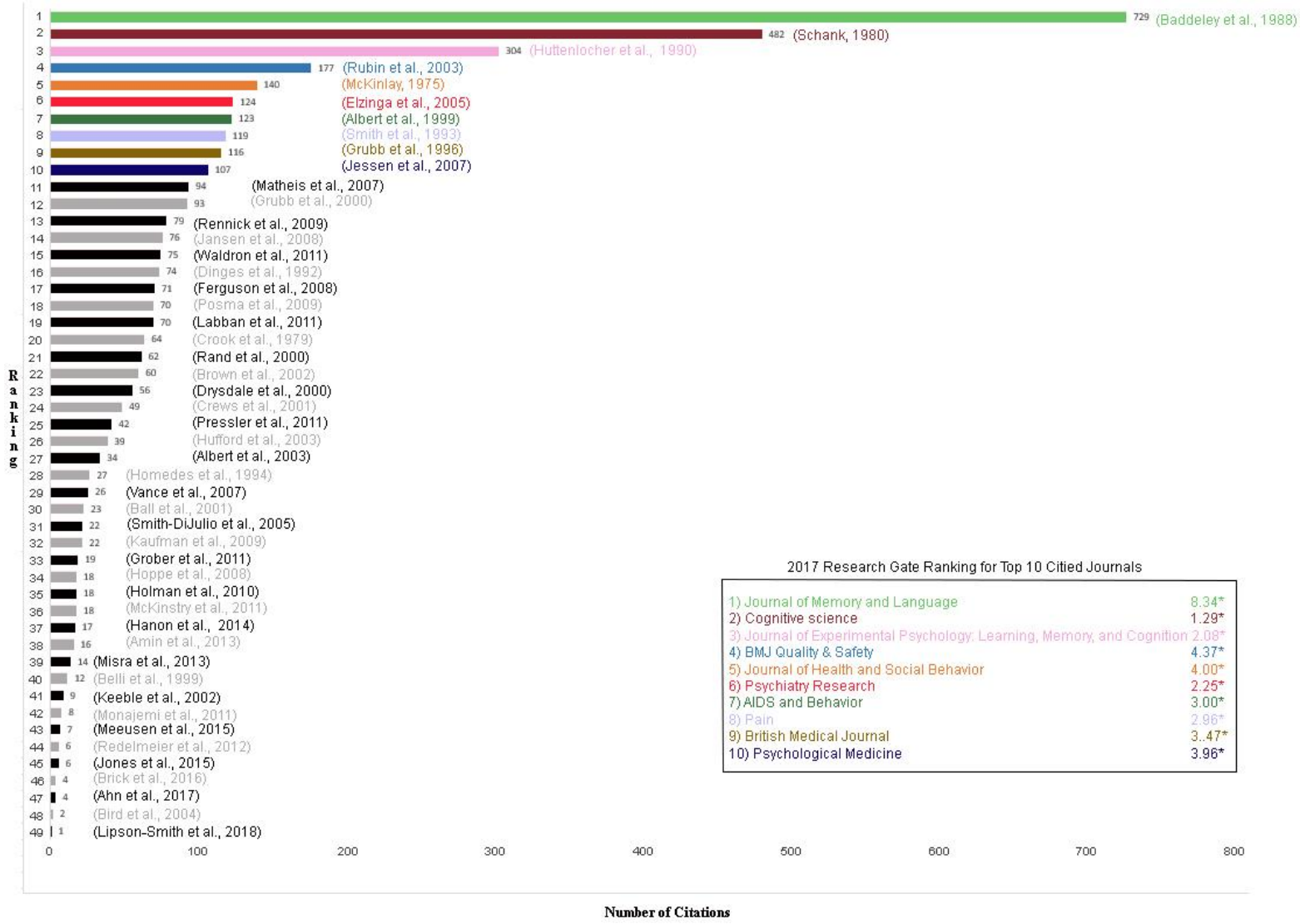


Figure B-5 Citations per paper

The benefit of the citation analysis is based on what Galton (1907) called the "*wisdom of crowds*". Citations gauge an aspect of a paper excellence or the impact of publications (van Raan, 1996), and so we counted the number of citations for each paper including the Research Gate journal rankings of the top ten cited papers to gauge their quality and add validity to the exploration of the literature. 10 of the 49 papers under review had at least 100 citations each and a Research Gate ranking ranging from 1.29 to 8.34, the next 18 papers assessed had between 50 and 100 citations each. Following this brief overview, we now move onto our research question.

B.5.2 RQ. What long term information retrieval/memory recall concepts have been reported *within* the context of the medical appointment and in what medical areas/conditions have they been reported?

The identified long-term memory concepts were evaluated for similarities and distinctions in order for them to be categorized into higher abstracted memory categories using the Tulving's Triarchic Theory of Memory (Figure B-3) to guide the creation of classifications resulting in Table B-7 (papers not included in this table did not *touch on* or *focus upon* any of these long-term memory types). The first major gap identifiable (from a visual perspective) is the lack of papers in the non-declarative category. On the other hand, when one considers that this form of long-term memory does not require conscious awareness and pertains to memories that are not easy to articulate, it is understandable from a patient/carer information retrieval/memory recall viewpoint why this is so.

As one might expect, declarative memory is where most research activity is evident as this refers to conscious thought. Declarative memory originally divided by Tulving (1972) into Episodic memory and Semantic memory, has since evolved to include other memory types as shown in Table B-7, the definitions of which we have put into Table B-8.

The concept with the greatest amount of interest is Episodic memory (first appearing in the papers under review in 1980) which appears eight times. One may ask why has there been such a focus on this area of long-term memory *within* the medical appointment? Episodic memory, according to Tulving (1983, 2002), is the capacity to engage in mental time travel, which is associated with his idea of *auto-noetic* (the ability to mentally place ourselves in the past, in the future, or in counterfactual situations) consciousness. From a medical appointment perspective, the profound information retrieval/memory recall observed in patients *during* the *elicitation* phase is very often episodic in nature where one must recall specific details of events including those outside of the appointment setting (such as the onset of a symptom prior to the appointment).

Indeed, in a study conducted by Gregory et al. (1991) they found that memories of an event change over time. When a patient is in a medical appointment and asked to recall an event in detail such as the onset of a current infection, the remembered date is likely to be shifted forward in time, and when little is known about the event it is liable to be shifted backwards (Brown et al., 1986). Unsurprisingly, recent events are better recalled than more remote ones (Rubin, 1982); and events which

have self-reference are remembered better than those which do not involve the self (a challenge for carers of patients) (Conway et al., 1996).

Table B-7 Frequency of long-term memory concepts using an expanded version of Tulving's Triarchic Theory of Memory *– those in grey are when a concept is just touched upon.*

	Decade	1975-1985	1986-1996	1997-2007	2008-2018	Totals	
Long Term Memory						Focus	Touched Upon
Declarative	Episodic	(Schank et al., 1980)	(Huttenlocher et al., 1990); (Smith et al., 1993); (Grubb et al., 1996)	(Drysdale et al., 2000); (Grubb et al., 2000); (Hufford et al., 2003)	(Grober et al., 2011); (Amin et al., 2013)	8	1
	Prospective				(Holman et al., 2010)	0	1
	Autobiographical		(Huttenlocher et al., 1990); (Dinges et al., 1992)	(Belli et al., 1999); (Ball et al., 2001); (Hufford et al., 2003)		1	4
	Semantic	(Schank et al., 1980)	(Smith et al., 1993);		(Amin et al., 2013); (Brick et al., 2016)	0	4
	Spatial			(Grubb et al., 1999); (Elzinga et al., 2005); (Matheis et al., 2007)	(Ferguson et al., 2008); (Amin et al., 2013);	4	1
Non- Declarative	Procedural			(Elzinga et al., 2005)	(Jansen et al., 2008)	0	2
	Classical Conditioning					0	0
	Priming					0	0

Several of these factors are clearly implicated in memory for medical history as health events are normally self-referential (except in the case of a carer) and may be recurring (especially true for chronic patients). Research shows that date accuracy can however be improved by using significant events as reference points (Loftus et al., 1983) or by reference to a personal timeline (Robinson, 1986). For example, linking the onset of an illness to an event such a family celebration which holds personal significance.

Of note is the reference to Autobiographical memory in four papers, yet it has been a focus of research in only one of the papers analysed. We find this of interest as

Autobiographical memory builds considerably on Episodic memory. As the name suggests Autobiographical memory from a patient perspective translates into their life as a patient, encompassing all the medically related events they have experienced including illnesses, medical appointments and so on.

Table B-8 Description of Declarative Memory Components

Term	Description	References
Episodic Memory	Episodic memories refer to particular episodes or occasions in our lives. They are linked to the time and place of the event in which the information was attained via sensory inputs. Episodic memories are more catalogued and forgotten very quickly. Episodic memory requires knowledge of the self.	Radvansky, 2017
Semantic Memory	Semantic memories are generalised and encyclopaedic in nature and are not tied to a specific time or location. As a stable knowledge that you share with society, once established these memories are forgotten extremely slowly and are highly interrelated. Semantic memory requires conscious awareness.	Radvansky, 2017
Spatial Memory	Spatial memory is that aspect of the memory responsible for the logging of information regarding the world/location a person lives in and involves spatial positioning. Having portrayals within working memory, STM and LTM, our spatial memory is vital for navigating to a location as it is akin to a cognitive map.	Radvansky, 2017
Autobiographical Memory	Autobiographical memory builds on episodic accounts, that is to say episodic memories (a series of individual events in the past) taken together make up a person's autobiographical memory or personal history that links a person to their past, present, and future self. In essence it is our unique life story.	Habermas & Bluck 2000, McAdams 2001
Prospective memory	Prospective memory involves an intent to carry out a future act being formed/encoded in memory. Later on, an encounter with an environmental stimulus acts like a memory trigger/prompt to perform that action.	Einstein & McDaniel, 1990; Harris, 1984; Harris & Wilkins, 1982; Meacham & Leiman, 1975

Studies of the ability to date events (such as the date a particular medical appointment occurred) using Autobiographical memory have shown that the dates given by people for personal events have a high probability of being in error, where dating is found to be based on inference, estimation and guesswork (Brown et al., 1986). The situation becomes all the more byzantine for patients with a chronic condition/s where multiple medical appointments occur with varying degrees of regularity. Gregory et al. (1991) have hypothesized that Autobiographical memories are at best interpretations of past events based on a combination of memory and belief rather than an actual precise record of the past. This suggests that memory for medical history is also likely to be influenced by the patient's beliefs about their health status and attitudes towards particular events (Cohen et al., 1995). Indeed, the degree to which this medical information fits into cognitive schemas has been reported to affect how well patients/carers can retrieve information at a later time (Rice et al., 1994).

Prospective memory (remembering to remember - Schonfield et al., 1979) appears only once as a major concept (in 2010) despite its importance *within* the medical appointment. For example, a patient may need to remember to report a new symptom or recall concerns that are occupying their thoughts. Both are important for the doctor to be aware of not just in terms of diagnosis and decision-making (Cohen et al., 1995) but also to ease the psychological burden the patient is carrying (Turner, 2000). The extent to which individuals must rely on strategic monitoring or spontaneous retrieval to realize delayed intentions seems to depend on a variety of factors, such as the importance of the ongoing task compared to the Prospective memory task, salience of Prospective memory targets, whether the cues are in the

focus of ongoing activities (focal cues) or whether they are more peripheral to ongoing activities (non-focal cues; Einstein et al., 2005; McDaniel et al., 2000), and when using one focal cue as opposed to multiple focal cues (Einstein et al., 2005; Cohen et al., 2008).

Kvavilashvili et al., (2001) report that Prospective memory failures represent 50-70 percent of everyday memory problems (see also Crovitz et al., 1984; Terry, 1988). This can be even more pronounced for chronic patients when one considers the considerable burdens of treatments (defined by May (2009) as the impact of the "*work of being a patient*" on functioning and well-being). This work includes drug management, self-monitoring, visits to the doctor, laboratory tests, lifestyle changes, and other actions that take place in addition to the other work patients and their caregivers must do as part of life (Eton, 2012; Tran, 2012). Coping with all these healthcare tasks requires a significant amount of additional time, physical effort, and cognitive effort (in the form of Prospective memory) from patients and caregivers, often leading to Prospective memory failures. Walter et al. (2014) state that Prospective memory failures can also affect our reputation and self-esteem, because a person who always remembers may be perceived as conscientious and well organized, while a forgetful person (for instance a patient/carer in a medical appointment) is often viewed as unreliable and disorganised (Ibid). This social perception may arise out of the conceptual link that is made between motivation and importance (Walter et al., 2014).

Having grasped the information retrieval/memory recall concepts reported regarding the medical appointment we also investigated the medical fields that had

been studied in relation to information retrieval/memory recall, where we set about categorising the medical area concepts by human system (Table B-9), including the year that a category first appeared as either a focus of research or was only touched upon in a paper.

The outcome of this examination shows that the medical disciplines most prevalent in the literature are the concepts falling under the Nervous System category which has 10 papers that focus on this area and another 13 that touch upon it. This is expected given the cognitive nature of information retrieval/memory recall. This medical area is followed by concepts under the Circulatory Systems class, which is anticipated given the prevalence of this condition, and which is the number one cause of death globally, where more people die annually from this category of disease than from any other cause. Indeed approximately 17.9 million people died from Cardiovascular disease in 2016, representing 31 percent of all global deaths (WHO, 2017).

Interestingly, the classifications of respiratory and endocrine have fared poorly in terms of becoming disciplines that have had any major research conducted (in the area of information retrieval/memory recall *within* the medical appointment) despite having being mentioned in several papers engaging in this area of research. Research in this medical system is important as individuals with Chronic Obstructive Pulmonary Disease (COPD) are reported to display *''significant, if not modest''* impairments, specifically, in abstract reasoning, memory, and speed of performance, as compared to controls (Crews, 2001).

Table B-9 ***Frequency of Medical System concepts*** *– those in grey are when a concept is just touched upon.*

	Decade	1975-1985	1986-1996	1997-2007	2008-2018	Focus	Touched Upon
Medical System	**Skeleton**			(Rand et al., 2000)		**0**	**1**
	Integumentary				**(Ahn et al., 2017)**	**1**	**0**
	Renal		(Homendes et al., 1994)	(Keeble et al., 2002)	(Hanon et al., 2014)	**0**	**3**
	Digestive	(Schank et al., 1980)		**(Ball et al., 2001)**	**(Misra et al., 2013);** (Jones et al., 2015); **(Brick et al., 2016);** (Lipson-Smith et al., 2018)	**3**	**3**
	Reproductive	(Smith-DiJulio et al., 2005)		(McKinlay et al., 1975)	**(Hoppe et al., 2008)**	**3**	**0**
	Immune			**(Albert et al., 1999);** (Rand et al., 2000); **(Albert et al., 2003);** (Vance et al., 2007)		**3**	**1**
	Endocrine			(Grubb et al., 2000); (Rand et al., 2000); (Brown et al., 2002);	(Kaufman et al., 2009); **(Grober et al., 2011);** (Waldron et al., 2011); (Redelmeier et al., 2012); (Hanon et al., 2014); (Jones et al., 2015); (Ahn et al., 2017)	**1**	**9**
	Circulatory		(Homendes et al., 1994); **(Grubb et al., 1996);**	**(Drysdale et al., 2000); (Grubb et al., 2000);** (Rand et al., 2000); **(Keeble et al., 2002);** (Hufford et al., 2003); **(Vance et al., 2007);** (Matheis et al., 2007)	(Kaufman et al., 2009); **(Pressler et al., 2011);** (McKinstry et al., 2011); **(Waldron et al., 2011);** (Monajemi et al., 2011); (Redelmeier et al., 2012); **(Hanon et al., 2014);** (Jones et al., 2015)	**8**	**9**
	Nervous	(Schank et al., 1980)	**(Baddeley et al., 1988);** (Dinges et al., 1992); **(Smith et al., 1993);**	(Drysdale et al., 2000); (Rand et al., 2000); (Crews et al., 2001); **(Albert et al., 2003);** (Bird et al., 2004); **(Elzinga et al., 2005);** **(Vance et al., 2007);** **(Jessen et al., 2007);** **(Matheis et al., 2007)**	**(Rennick et al., 2009);** (Kaufman et al., 2009); (McKinstry et al., 2011); (Grober et al., 2011); (Waldron et al., 2011); **(Amin et al., 2013);** (Hanon et al., 2014); (Jones et al., 2015); **(Meeusen et al., 2015);** (Lipson-Smith et al., 2018)	**10**	**13**
	Respiratory		(Homendes et al., 1994); (Grubb et al., 1996);	(Rand et al., 2000); **(Crews et al., 2001);** (Keeble et al., 2002);	(Kaufman et al., 2009); (Pressler et al., 2011); (Monajemi et al., 2011); (Hanon et al., 2014); (Jones et al., 2015)	**1**	**9**

Prigatano et al. (1983) has postulated that decreased cerebral blood flow and oxygen consumption would explain such declines in cognitive performance in respiratory patients. Respiratory diseases are the main cause of deaths in the EU, with 422

deaths in 2016 – or 8.2 percent of all deaths (Eurostat, 2019). Therefore, one would expect a greater number of research papers on information retrieval/memory recall *within* the *elicitation* phase of the medical appointment for respiratory patients given how critical an accurate diagnosis is in treating these patients and reducing these figures.

We concluded our investigation into the medical areas by highlighting the pervasiveness of age-related medical areas in the reviewed literature in Table B-10. Geriatric medicine features frequently as a focus of research (11 papers), which is not altogether surprising given an ageing populace, with an extended life expectancy, resulting in the increased likelihood of chronic diseases which, according to WHO, typically manifest in the later stages of life (WHO, 2018). To prevent, as far as possible, the onset of chronic illnesses in the greying society, research (in an extensive array of disciplines) has gained significantly in importance. This of course also holds for memory, as this is known to be affected by age (Jansen et al., 2008; Posma et al., 2009; Crook et al., 1979; Grober et al., 2011; Hanon et al., 2014; Jones et al., 2015), where research shows that older adults' recall of past experiences is often more incomplete than those of younger people (Cohen et al., 1988; Holland et al., 1990).

Remarkably from 1997 onwards, we see outputs in the area of Paediatric medicine where memory issues manifest themselves primarily due to the effects of persistent conditions such as in chronic kidney disease (Fennell et al., 1990c; Gipson et al. 2006). One may ask if this is the case why there are not more papers in Table B-9 under the Renal category? The reason may be that the parent/carer is usually the

one that engages in the majority of the dialogue with the doctor when recalling events such as symptoms etc. even though the child may actually be the one with information retrieval/memory recall issues. This does of course change as the child reaches adulthood and has a greater degree of involvement in the management of their healthcare, providing of course they are capable of doing so.

Table B-10 Frequency of age-related medical Area concepts *– those in grey are when a concept is just touched upon*

	Decade	1975-1985	1986-1996	1997-2007	2008-2018	Focus	Touched Upon
Age Related Medical Area	**Geriatric**	(Crook et al., 1979)	(Grubb et al., 1996);	(Albert et al., 1999); (Belli et al., 1999); (Brown et al., 2002); (Bird et al., 2004); (Vance et al., 2007); (Jessen et al., 2007)	(Jansen et al., 2008); (Posma et al., 2009); (Pressler et al., 2011); (Grober et al., 2011); (Waldron et al., 2011); (Hanon et al., 2014); (Jones et al., 2015);	**11**	**4**
	Pediatric			(Rand et al., 2000); (Ball et al., 2001); (Bird et al., 2004); (Rennick et al., 2009)	(Ahn et al., 2017)	**3**	**2**

We conclude our RQ by postulating the impacts that our examination has on the core stakeholders in the medical appointment area: the academic, the doctor and of course the patient/carer (Table B-11). The academic becomes drawn to future research opportunities, and questions that need to be answered. For example, do we know or really comprehend the dynamics at play when a doctor asks a patient/carer a specific question that requires the patient/carer to recall information from memory and the different types of memory components therein? (for instance, Episodic memory or Prospective memory). Do we know all that is required to be known regarding information retrieval/memory recall and the accuracy of the medical history data retrieved from memory so that we may then remedy the issues with

same? How can this advancement in our understanding of memory recall/information retrieval help us advance solutions to design solution to address same?

Interestingly, a recent Action Design Research (ADR) project undertaken by an IS researcher illustrates the tangible benefits of understanding memory recall/information retrieval (and LTM components) and applying same to the design of a solution to aid Cystic Fibrosis (CF) patients/carers memory recall/information retrieval (Twomey et al., 2018; Twomey et al., 2020). The artefact designed, in this case a pretotype (paper-based prototype) in the form of a check list), not only significantly augmented memory recall *within* the medical appointment, it also reduced patient/carer stress and increased their sense of empowerment (Ibid). Moreover, it has since being distributed to CF patients/carers within the Republic of Ireland and the UK and has since gone to seven other countries for review by their relevant CF bodies/associations (Twomey et al., 2020). The researcher claims that the success of the design is due to the check list design actually mapping "*to aid the declarative long-term memory component drawn upon by the patient or caregiver during the medical appointment"* (Twomey et al., 2020, p. 16).

McKinstry et al (2011) report that doctors rarely use approaches to try to ameliorate the poor information retrieved by the patient/carer *within* the *elicitation* phase of medical appointment despite the effect that such poor data has on their ability to make an accurate diagnosis. Therefore, our research may result in an enriched

understanding of information retrieval/memory recall, its constituents, and illnesses that are associated with information retrieval/memory recall deficits.

This knowledge may therefore act as a trigger for some medical community/doctors to change or adapt their communication practices *within* the medical appointment, such as checking for patients recall of information (Bartlett et al., 1984; Schillinger et al., 2003) or perhaps working with the IS community in developing solutions to aid patient/carer memory recall. Interestingly, in the before mentioned Twomey et al., (2018) paper, they report that, although initially cautious of the check list and of supplying carers with medical information, "*the Paediatric unit are now actively providing carers with their child's medical data to help them record their medical data on their check lists"* (Twomey et al., 2018, p.8).

Finally, for the patient our research contributes a conscious awareness of information retrieval/memory recall *within* the medical appointment, the types of memory involved, the consequences of deficient data retrieval and poor data accuracy on the outcome of the appointment. However, they may also become mindful of practises that can aid information retrieval/memory recall that they can use as a way to augment their memory. Our research may also help answer questions for some patients regarding their condition and issues with information retrieval/memory recall resulting in a new discussion with their doctor that may go to assuage any worries they have regarding same.

Table B-11 Impact Potential of Review - Research Question

	Academic	Doctor	Patient/Carer
Research Q	**Inform** • Enlightening academics to the importance of data accuracy *within* the medical appointment including the role that long-term memory and its subcomponents plays *within* this environment. • The study also highlights the association of memory recall issues and many chronic conditions, which when taken together, present many research opportunities including prospects for IS in the areas of people, process, technology and data, to increase our understanding surrounding memory recall /information retrieval *within* the medical appointment. This augmented comprehension will lead to the development of innovative solution to ameliorated the issue of poor memory recall, as achieved by Twomey et al. (2018/2020) in their research.	**Influence** • Research shows that doctors seldom use techniques proven to improve recall in terms of both phone and one-on-one appointments (McKinstry et al., 2011, Martin 2014), despite the fact that it has been shown that better outcomes accrue when clinicians check patients' recall of information (Bartlett et al., 1984; Schillinger et al., 2003). • Our research gives a greater understanding of how long-term memory has evolved to include new components including autobiographical memory, prospective memory and the importance of same *within* the *elicitation* phase of the medical appointment. • In tandem with this, our exploration leads to an augmented comprehension of memory recall issues and their association with certain chronic conditions such as COPD within the medical community. Therefore, as a result of this increased comprehension, doctors may start to adapt their communication styles/approach *within* the medical appointment.	**Awareness** • A conscious awareness of memory recall by patients/carers, the types of memory involved, the impact that data accuracy has on a medical appointment outcome, and a new literacy that can only benefit them in future conversations with their doctor. • They may also become more conscious of how inaccurate their memory can be, for example where their ability to date episodes is built on deduction, approximation and conjecture (Brown et al., 1986). • In tandem with this, they may become cognisant of techniques that aid memory recall such as using significant occasions as points of reference or data points (Loftuis et al., 1983) or by locus to one's own history or diary (Robinson, 1986). • Patients too may wonder if the information retrieval issues that they are experiencing *within* the medical appointment are in any way related to their medical condition, and if so, how this may be addressed, thereby opening up new conversations with their doctor.

B.6 Summary & Concluding Remarks

Our study set out to highlight the importance of effective communication between a doctor and patient/carer *within* the medical appointment process, where the key purpose of the clinical encounter is arriving at a correct decision/diagnosis via information that should be accurate, timely and relevant. Additionally, we underline the relationship between information retrieval/memory recall by the patient/carer, and the quality of information imparted to the doctor (and the doctor's ability to make an accurate diagnosis) *within* the *elicitation* phase of the medical appointment.

Using a systematic approach to the literature review we deployed Webster and Watsons (2002) Concept-Centric Matrix approach in conjunction with the adoption of an eight-step process (c.f. Finney and Corbett's, 2007; Alhassan et al., 2016), with the initial selection activity returning 1,811 papers. Following rigorous selection and exclusion criteria, 49 papers were found to serve the research objective, answering our research question: *What long term information retrieval/memory recall concepts have been reported within the context of the medical appointment, and in what medical areas/conditions have they been reported?* These papers were then put through an in-depth content analysis using an open coding analysis technique.

The review of information retrieval/memory recall *within* the medical appointment exposes the need for an increased understanding of Autobiographical memory and Prospective memory *within* the medical appointment. The study also reveals some progress in exploring information retrieval/memory recall in a number of human

systems/disease states, however, the investigation uncovers a significant number that still require further investigation. Pursuing research in information retrieval/memory recall (*within* the medical appointment) within these human systems/disease states is appropriate due to the vast numbers of patients with chronic diseases attending medical appointments globally on a daily basis (for instance, approximately 45%, or 133 million of all Americans suffer from at least one chronic disease (Raghupathi & Raghupathi, 2018)).

Finally, the exploration highlights the future research opportunities that the review has presented. What is quite striking about the review is the scarcity of IS publications in information retrieval/memory recall *within* the medical appointment (which is essentially a data retrieval/data quality issue, albeit *within* a unique environment). While some within the IS community may take the view that this research and its findings are only of interest to a medical audience and have no place within an IS journal, we would disagree with this contention and believe that the opportunities for IS research are rich (as illustrated in Twomey et al., 2018, Twomey et al., 2020) and are very worthy of further consideration. To this end we have conceptualized our research by creating a model of the *elicitation* phase of the medical appointment process in Figure B-6. This model is akin to Figure B-1 but shows the advancement of our knowledge at the end of our exploration of information retrieval/memory recall *within* the medical appointment. The model uncovers a number of possible directions for future research, especially for those in IS. There are many research questions that the model raises/provokes, for example, do we know enough regarding patients/carers and the medical appointment process to be able to create technical solutions to improve the data accuracy of medical

history communicated to the doctor? How can we ensure that we have a complete accurate record of a patient's past? It will also be important for us to hypothesize the relationships that exist between declarative LTM (and its components) and the other information retrieval/memory recall challenges (in addition to "*Disease Type*", that will need to be explored in the future) that exist for patients/carers *within* the medical appointment. Moreover, it will become important for IS researchers to become involved in the creation of innovative solutions in order to ameliorate the challenges of memory recall/information retrieval *within* the medical appointment. It would seem that the IS community has a significant role to play in helping to answer these questions. And so, this review and the model therein provide a robust foundation for those in practice/IS research, who strive to understand the dynamics of memory recall/information retrieval *within* the medical appointment, or those who are searching for novel ways to ameliorate the effects of poor memory recall on the diagnostic process *within* this environment.

Our research has three key limitations. Firstly, the initial search emphasis was only conducted on peer reviewed academic journals in the area of information retrieval/memory recall *within* the medical appointment. This may well have excluded publications in books or websites articles that may have enriched the review further. Also, as previously mentioned there are other areas/environs that are outside the confines of our search criteria (*within* the medical appointment) that may enhance our comprehension of patient/carer information retrieval/memory recall *within* the medical appointment.

This may of course be true, only future research will show if this is the case; the review therefore highlights three possible areas for future research; that of patient/carer information retrieval/memory recall *before*, *after* and *between* medical appointments. Secondly, it could be argued that our search criteria are too narrow and that indeed we may be missing some seminal papers in the review. In counterpoint to this however, we have searched 39 databases, crossing the divides of many disciplines (as advised by Webster & Watson, 2002) to obtain as holistic a view of the literature as possible.

Thirdly, there is a lack of insight regarding the actual challenges that patients/carer actually experience/have regarding their ability to remember key medical events and information. It is important to understand these challenges so that we may come to design solutions to remedy same, and so this is an opportunity for further research. Moreover, there is an opportunity to explore and understand the solutions that currently exist that address these information retrieval/memory recall challenges.

In summation, there is a real necessity for the information retrieval/memory recall process *within* the medical appointment to be fully comprehended, to be re-examined by other disciplines in order to augment our understanding of the dynamics at play in this environment. For the problem/s and challenges of information retrieval/memory recall and data accuracy experienced by patient/carers/doctors *within* this unique environment to be further explored and challenged, leaving behind myopic positions, where we observe information retrieval/memory recall *within* the medical appointment through new lenses,

bringing fresh perspectives, novel opportunities, contributions to knowledge and innovative solutions to those who toil against the burden of living with a chronic disease and the challenges/issues of information retrieval/memory recall.

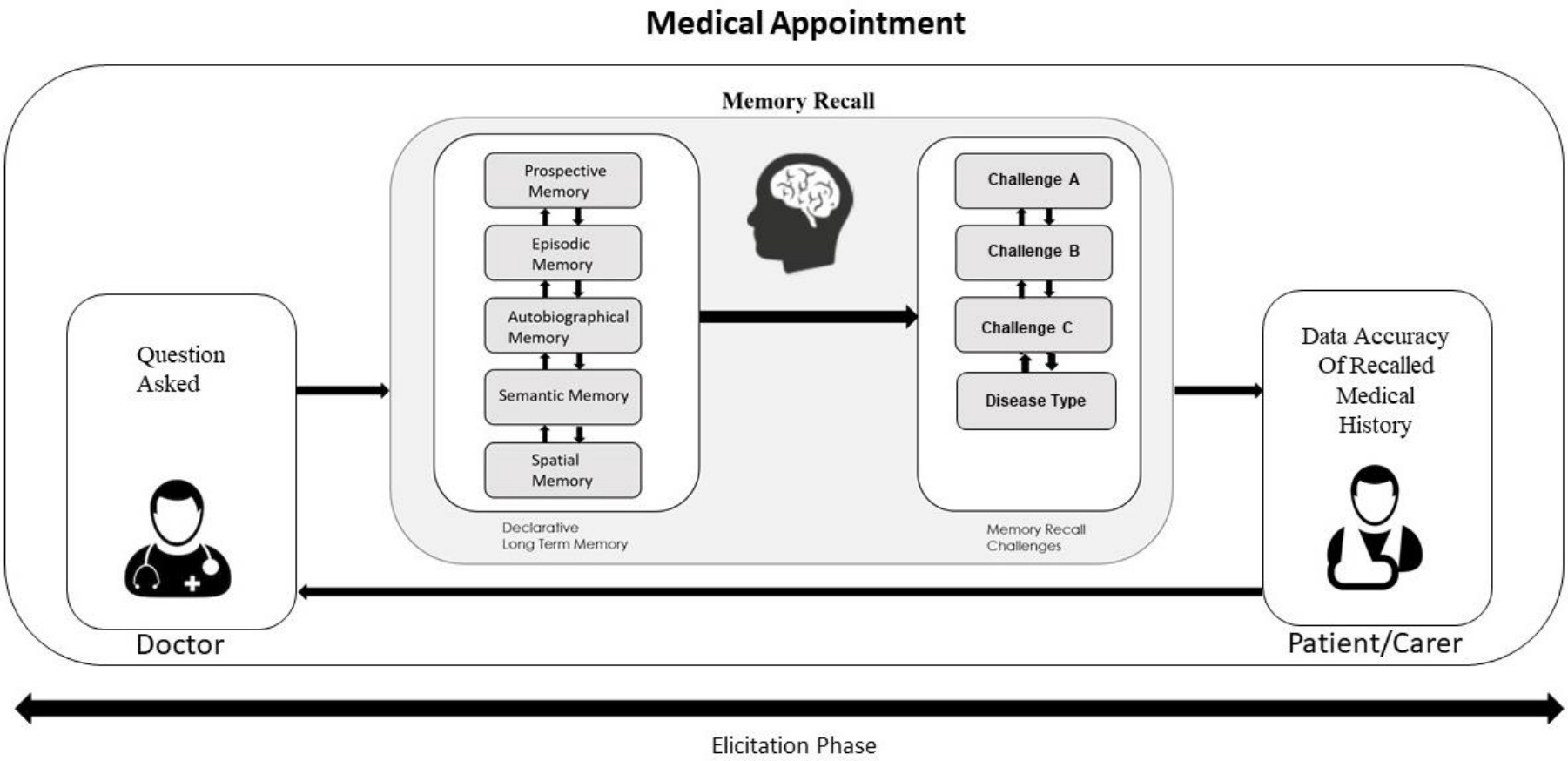


Figure B-6 Elicitation phase of the medical appointment

B.7 References

Ahn CS., Culp L., Huang WW., Davis SA., Feldman SR., (2017) Adherence in dermatology. *J Dermatolog Treat*. 28(2):94-103.

Albert, S.M., Weber, C.M., Todak, G. et al. *AIDS Behav* (1999) 3: 121.

Albert, Steven M; Flater, Susanne R; Clouse, Ronda; Todak, George; Stern, Yaakov; Marder, Karen. (2003). Medication Management Skill in HIV: I. Evidence for Adaptation of Medication Management Strategies in People with Cognitive Impairment. II. Evidence for a Pervasive Lay Model of Medication Efficacy. *AIDS and Behaviour,* Volume 7, Issue 3.

Alhassan, I., Sammon, D., Daly, M., (2016) Data governance activities: an analysis of the literature, *Journal of Decision Systems*, 25:sup1, 64-75.

Amin H, Malik AS. (2013) Human memory retention and recall processes. A review of EEG and fMRI studies. *Neurosciences* (Riyadh). 18(4):330-44.

Atkinson, R. C., & Shiffrin, R. M. (1968). Human memory: A proposed system and its control processes. *The Psychology of Learning and Motivation*, 2, 89–195.

Baddeley, Alan; Wilson, Barbara (1988). Comprehension and working memory: A single case neuropsychological study. *Journal of Memory and Language*, Volume 27, Issue 5.

Baddeley, A., Eysenck, M., Anderson, M. (2015). *Memory* (2nd edition), Psychological Press.

Balint, M. (1961) The other part of medicine. *Lancet*, 1, 40–42.

Ball CT, O'Callaghan J. (2001) Judging the accuracy of children's recall: a statement-level analysis. *J Exp Psychol Appl*. Dec;7(4):331-45.

Bartlett, E. E., Grayson, M., Barker, R., Levine, D. M., Golden, A., & Libber, S. (1984). The effects of physician communication skills on patient satisfaction, recall and adherence. *Journal of Chronic Diseases*, 37, 755–764.

Belli RF, Weiss PS, Lepkowski JM, (1999). Dynamics of survey interviewing and the quality of survey reports: age comparisons. Schwarz N, Park D, Knauper B, Sudman S, ed. *Cognition, Aging and Self-Reports* 303 -307. Psychology Press, Philadelphia, PA.

Berner, E., Graber, M. (2008), Overconfidence as a Cause of Diagnostic Error in Medicine, *The American Journal of Medicine*, Volume 121, Issue 5, S2 - S23

Bhattacherjee, A. (2012), *Social Science Research: Principles, Methods, and Practices*, 2nd ed., Global Text Project, Athens.

Bird, Steven J; (2004). Hands-on versus demonstration teaching methods: the effect on memory in older adults. The University of Toledo Digital Repository.

Bradshaw, P. W., Ley, P., Kincey, J. A. and Bradshaw, J. (1975), Recall of Medical Advice: Comprehensibility and Specificity. *British Journal of Social and Clinical Psychology*, 14: 55-62.

Brick C., McCully SN., Updegraff JA., Ehret PJ., Areguin MA., Sherman DK. (2016) Impact of Cultural Exposure and Message Framing on Oral Health Behaviour: Exploring the Role of Message Memory. *Med Decis Making*. 36(7):834-43.

Brown, N.R., Shevell, S.K. and Rips, L.J. (1986). Public memories and their personal context. In D.C. Rubin (ed). *Autobiographical memory*. Cambridge University Press.

Brown S., Park D., (2003) Theoretical Models of Cognitive Aging and Implications for Translational Research in Medicine. *The Gerontologist*, Volume 43, Issue suppl_1, Pages 57–67.

Brown S., Park D., (2002) Roles of age and familiarity in learning health information, *Educational Gerontology*, 28:8, 695-710.

Carley, K. (1993). Coding choices for textual analysis: A comparison of content analysis and map analysis. *Sociological Methodology*, 23, 75–126.

Chafe W. (1990). Some things that narratives tell us about the mind. *In Narrative Thought and Narrative Language,* ed. BK Britton, AD Pelligrini, pp. 79–98. Hillsdale, NJ: Erlbaum.

Cohen, A. L., Jaudas, A., & Gollwitzer, P. M. (2008). Number of cues influences the cost of remembering to remember. *Memory & Cognition*, 36(1), 149–156.

Cohen, G., & Faulkner, D. (1988). Life span changes in autobiographical memory. In M. M. Gruneberg, R. N. Sykes, & P. E. Morris (Eds.), *Practical aspects of memory*. - Current issues and theory. New "York: Wiley.

Cohen, Gillian, and Rosalind Java. (1995). "Memory for Medical History: Accuracy of Recall." *Applied Cognitive Psychology* 9 (4): 273–88.

Conway, M. A. (1996). Autobiographical memory. In E. L. Bjork & R. A. Bjork (Eds.), *Memory*. San Diego, CA: Academic Press.

Corbin, J.M. and Strauss, A. (1990), Grounded theory research: procedures, canons, and evaluative criteria, *Qualitative Sociology*, Vol. 13 No. 1, pp. 3-21.

Corbin, J., & Strauss, A. (2008). *Basics of qualitative research*. (3rd ed.). Thousand Oaks, CA: Sage Publications, Inc.

Crews WD, Jefferson AL, Bolduc T, Elliott JB, Ferro NM, Broshek DK, Barth JT, Robbins MK. (2001). Neuropsychological dysfunction in patients suffering from end-stage chronic obstructive pulmonary disease. *Arch Clin Neuropsychol*. 16(7):643-52.

Crook, T., Ferris, S. and McCarthy, M. (1979), The Misplaced-Objects Task: A Brief Test for Memory Dysfunction in the Aged. *Journal of the American Geriatrics Society*, 27: 284-287.

Crovitz, H., & Daniel, W. (1984). Measurements of everyday memory: Toward the prevention of forgetting. *Bulletin of the Psychonomic Society*, 22, 413–414.

Cushing, A.W. (2016). 'History of the doctor-patient relationship', in Brown et al., (1st ed.) *Clinical Communication in Medicine*, Wiley-Blackwell pp 23-41.

Dinges, D. F., Whitehouse, W. G., Orne, E. C., Powell, J. W., Orne, M. T., & Erdelyi, M. H. (1992). Evaluating hypnotic memory enhancement (hypermnesia and reminiscence) using multi-trial forced recall. *Journal of Experimental Psychology: Learning, Memory, and Cognition*, 18(5), 1139-1147.

Drysdale EE, Grubb NR, Fox KA, O'Carroll RE. (2000) Chronicity of memory impairment in long-term out-of-hospital cardiac arrest survivors. *Resuscitation*; 47:27–32.

Ebbinghaus, H. (1885/1964). *Memory: A contribution to experimental psychology*. Oxford: Dover.

Einstein, G. O., & McDaniel, M. A. (1990). Normal aging and prospective memory. *Journal of Experimental Psychology: Learning, Memory, and Cognition*, 16(4), 717.

Einstein, G. O., & McDaniel, M. A. (2005). Prospective memory multiple retrieval processes. *Current Directions in Psychological Science*, 14(6), 286–290.

Einstein, G. O., McDaniel, M. A., Thomas, R., Mayfield, S., Shank, H., Morrisette, N., et al. (2005). Multiple processes in prospective memory retrieval: Factors determining monitoring versus spontaneous retrieval. *Journal of Experimental Psychology: General*, 134, 327–342.

Elzinga, B. M., Bakker, A., Bremner, J. D. (2005). "Stress-induced cortisol elevations are associated with impaired delayed, but not immediate recall," *Psychiatry Research*, vol. 134, no. 3, pp. 211–223, 2005.

Eton DT, Ramalho de Oliveira D, Egginton JS, Ridgeway JL, Odell L, May CR, et al. (2012). Building a measurement framework of burden of treatment in complex patients with chronic conditions: a qualitative study. *Patient Relat Outcome Meas*. 3:39–49.

Eurostat (2019) Respiratory diseases statistics. https://ec.europa.eu/eurostat/statistics-explained/index.php/Respiratory_diseases_statistics#Deaths_from_diseases_of_the_respiratory_system [last visited 03/03/2020].

Fennell RS, Fennell EB, Carter RL, et al. (1990c). A longitudinal study of the cognitive function of children with renal failure. *Pediatr Nephrol* 4:11–15.

Ferguson, C.J., Cruz, A.M. & Rueda, S.M. (2008). Gender, video game playing habits and visual memory tasks. *Sex Roles* 58: 279.

Finney S., Corbett, M. (2007) ERP implementation: a compilation and analysis of critical success factors, *Business Process Management Journal*, Vol. 13 Issue: 3, pp.329-347.

Galton, F. (1907). Vox populi. *Nature*, 75, 450–451.

Gandhi, J., (2014), Re: William Osler: A Life in Medicine, BMJ, https://www.bmj.com/content/321/7268/1087.2/rr/760724 [Last accessed 13/11/2019]

Gipson DS, Hooper SR, Wetherington CE, et al. (2006) Memory and executive functions in pediatric kidney disease. *Child Neuropsychol* 12:1–15.

Glaser, B. (1978). *Theoretical Sensitivity*. Mill Valley, CA: Sociology Press.

Glaser, B. G. (1992). *Emergence vs forcing: Basics of grounded theory analysis*. Mill Valley, CA: Sociology.

Glaser, B. G., & Holton, J. (2004). Remodelling grounded theory. Forum Qualitative Sozialforschung/Forum: *Qualitative Social Research*, 5(2), Art. 4.

Goode, S., & Gregor, S. (2009). Rethinking organisational size in IS research: Meaning, measurement and redevelopment. *European Journal of Information Systems*, 18, 4–25.

Grahlmann, K. R., Helms, R. W., Hilhorst, C., Brinkkemper, S., & van Amerongen, S. (2012). Reviewing enterprise content management: A functional framework. *European Journal of Information Systems*, 21, 268–286.

Gregory, S., bishop, J., and Sheldon, S. (1991) Remembering past events: The Parents Tale. Paper presented to the *British Psychological Society Developmental Section Conference,* Cambridge.

Grober, E., Hall, C. B., Hahn, S. R., & Lipton, R. B. (2011). Memory Impairment and Executive Dysfunction are Associated with Inadequately Controlled Diabetes in Older Adults. *Journal of Primary Care & Community Health*, 2(4), 229–233.

Grubb Neil R, O'Carrol Ronan, Cobbe Stuart M, Sirel Jane, Fox Keith A A. (1996). Chronic memory impairment after cardiac arrest outside hospital. *BMJ* 313 :143.

Grubb NR, Fox KA, Smith K, Best J, Blane A, Ebmeier KP, Glabus MF, O'Carroll RE. (2000). Memory impairment in out-of-hospital cardiac arrest survivors is associated with global reduction in brain volume, not focal hippocampal injury. *Stroke.* 31:1509–1514.

Habermas T, Bluck S. (2000) Getting a life: the emergence of the life story in adolescence. *Psychol. Bull*. 126:748–69.

Hampton, J. R., Harrison, M. J., Mitchell, J. R., Prichard, J. S., & Seymour, C. (1975). Relative contributions of history-taking, physical examination, and laboratory investigation to diagnosis and management of medical outpatients. *British Medical Journal*, 2(5969), 486–489.

Hanon O., Vidal JS., de Groote P., Galinier M., Isnard R., Logeart D., Komajda M. (2014) Prevalence of memory disorders in ambulatory patients aged ≥70 years with chronic heart failure (from the EFICARE study). *Am J Cardiol*. 1;113(7):1205-10.

Harris, J. E. (1984). Remembering to do things: A forgotten topic. In J. E. Harris & P. E. Morris (Eds.), *Everyday memory actions and absentmindedness*. London: Academic.

Harris, J. E., & Wilkins, A. J. (1982). Remembering to do things: A theoretical framework and an illustrative experiment. *Human. Learning*, 1, 123–136.

Helmericks, S. G., Nelsen, R. L., & Unnithan, N. P. (1991). The researcher, the topic, and the literature: A procedure for systematizing literature searches. *Journal of Applied Behavioral Science*, 27(3), 285-294.

Holland, C. A., & Rabbitt, P. M. A. (1990). Autobiographical and text recall in the elderly: An investigation of a processing resource deficit. *Quarterly Journal of Experimental Psychology*, 42A, 441–470.

Holman, Jeff and Zaidi, Farhan, (2010). *The Economics of Prospective Memory*. Available at SSRN: https://ssrn.com/abstract=1662183. [Last accessed 05/09/2018].

Homedes, Nuria, Ugalde, Antonio (1994). Research on patient compliance in developing countries. *Bulletin of PAHO*, 28(l).

Hoppe MJ, Morrison DM, Gillmore MR, Beadnell B, Higa DH, Leigh BC. (2008). Agreement of daily diary and retrospective measures of condom use. *AIDS and behaviour*. 12(1):113-117.

Hufford M.R; Shiffman S. (2003). Assessment Methods for Patient-Reported Outcomes. *Disease Management & Health Outcomes*, Volume 11, Issue 2.

Huttenlocher, Janellen, Hedges, Larry V., Bradburn, Norman M. (1990). *Journal of Experimental Psychology: Learning, Memory, and Cognition*, Vol 16(2), 196-213.

Jansen J, van Weert J, van der Meulen N, van Dulmen S, Heeren T, Bensing J. (2008) Recall in older cancer patients: measuring memory for medical information. *Gerontologist*, 48(2):149-57.

Jessen F, Wiese B, Cvetanovska G, Fuchs A, Kaduszkiewicz H, Kölsch H, Luck T, Mösch E, Pentzek M, Riedel-Heller SG, Werle J, Weyerer S, Zimmermann T, Maier W, Bickel H. (2007) Patterns of subjective memory impairment in the elderly: association with memory performance. *Psychol Med.* 37(12):1753-62.

Jones G, Tabassum V, Zarow GJ, Ala TA. (2015). The inability of older adults to recall their drugs and medical conditions. *Drugs Aging*. 32(4):329-36.

Kassirer JP. (1983) Teaching clinical medicine by iterative hypothesis testing. Let's preach what we practice. *N Engl J Med*.309(15):921-923

Kaufman G1, Birks Y. (2009) Strategies to improve patients' adherence to medication. *Nurs Stand*. 23(49):51-7.

Keeble, W; Cobbe, S M. (2002). Patient recall of medication details in the outpatient clinic. Audit and assessment of the value of printed instructions requesting patients to bring medications to clinic. *Postgraduate medical journal*, Volume 78, Issue 922.

Kessels R., Patients' memory for medical information. (2003). J R Soc Med 96:219–222.

Kitchenham, B., & Charters, S. (2007). *Guidelines for performing systematic literature reviews in software engineering* (Technical Report No. EBSE-2007-01). Keele, UK: Keele University.

Klein, S. B., Cosmides, L., Tooby, J., & Chance, S. (2002). Decisions and the evolution of memory: Multiple systems, multiple functions. *Psychological Review*, 109, 306–329.

Kvavilashvili, L., Messer, D. J., & Ebdon, P. (2001). Prospective memory in children: The effects of age and task interruption. *Developmental Psychology*, 37(3), 418.

Labban JD, Etnier JL. (2011) Effects of acute exercise on long-term memory. *Res Q Exerc Sport.* 82(4):712-21.

Labov W. (1982) Speech actions and reaction in personal narrative. In *Analyzing Discourse: Text and Talk*, ed.

Langewitz W, Ackermann S, Heierle A, Hertwig R, Ghanim L, Bingisser R. (2015) Improving patient recall of information: harness the power of structure. Patient Educ Couns., 98:716–21.

Lazare A., Putnam S.M., Lipkin M. (1995) Three Functions of the Medical Interview. In: Lipkin M., Putnam S.M., Lazare A., Carroll J.G., Frankel R.M. (eds) *The Medical Interview. Frontiers of Primary Care*. Springer, New York, NY.

Ley et al., (1973), A method for increasing patients' recall of information presented to them. *Psychological Medicine*,3, 217-220.

Linde C. (1993). *Life Stories: The Creation of Coherence*. New York: Oxford Univ. Press.

Lipson-Smith R., Hyatt A., Murray A., Butow P., Hack TF., Jefford M., Ozolins U., Hale S., Schofield P. (2018) Measuring recall of medical information in non-English-speaking people with cancer: A methodology. *Health Expect*. 21(1):288-299.

Loftus et al., (1983) Since the eruption of Mount St. Helens has anyone beaten you up? Improving the accuracy of retrospective reports and landmark events. *Memory and Cognition,* 11, 114-120.

Martin L., Dimatteo M., (2014) *The Oxford Handbook of Health Communication, Behaviour Change, and Treatment Adherence*. Oxford University Press.

Matheis RJ1, Schultheis MT, Tiersky LA, DeLuca J, Millis SR, Rizzo A. (2007) Is learning and memory different in a virtual environment? *Clin Neuropsychol*. 21(1):146-61.

May C, Montori VM, Mair FS. (2009). We need minimally disruptive medicine. *BMJ*. 339: b2803.

Meacham, J. A., & Leiman, B. (1975). Remembering to perform future action. In U. Neisser (Ed.), *Memory observed* (pp. 327– 336). San Francisco: Freeman.

Meeusen AJ., Porter R. (2015) Patient-Reported Use of Personalized Video Recordings to Improve Neurosurgical Patient-Provider Communication. *Cureus*. 2;7(6): e273.

McAdams DP. (2001) The psychology of life stories. *Rev. Gen. Psychol*. 5:100–22.

McDaniel, M. A., & Einstein, G. O. (2000). Strategic and automatic processes in prospective memory retrieval: A multi-process framework. *Applied Cognitive Psychology*, 14(7), S127–S144.

McGuire, L. C. (1996). Remembering what the doctor said: Organization and older adults' memory for medical information. *Experimental Aging Research*, 22, 403–428.

McKinlay, J. (1975). Who is Really Ignorant--Physician or Patient? *Journal of Health and Social Behaviour*, 16(1), 3-11.

McKinstry B1, Watson P, Elton RA, Pinnock H, Kidd G, Meyer B, Logie R, Sheikh A. (2011). Comparison of the accuracy of patients' recall of the content of telephone and face-to-face consultations: an exploratory study. *Postgrad Med J*. 87(1028):394-9.

Misra S1, Daly B, Dunne S, Millar B, Packer M, Asimakopoulou K. (2013) Dentist-patient communication: what do patients and dentists remember following a consultation? Implications for patient compliance. *Patient Prefer Adherence*. 17;7:543-9.

Monajemi, Alireza; Rikers, Remy M.J.P. (2011) The role of patient management in medical expertise development: Extending the contemporary theory. *International Journal of Person Centered Medicine*, [S.l.], v. 1, n. 1, p. 161-166.

Osler, S.W. (1914) *Aequinimitas. With Other Addresses to Medical Students, Nurses and Practitioners of Medicine*, second edn. HK Lewis, London.

Personal Injury Team Ireland (2017). Medical Negligence in hospitals in Ireland. http://www.personalinjuryireland.ie/medical-negligence-in-hospitals-in-ireland.

Posma ER, van Weert JC, Jansen J, Bensing JM. (2009). Older cancer patients' information and support needs surrounding treatment: An evaluation through the eyes of patients, relatives and professionals. *BMC Nurs*. 19;8:1.

Pressler SJ, Therrien B, Riley PL, Chou CC, Ronis DL, Koelling TM, Smith DG, Sullivan BJ, Frankini AM, Giordani B. (2011). Nurse-Enhanced Memory Intervention in Heart Failure: the MEMOIR study. *J Card Fail*. (10):832-43.

Prigatano, G. P., Parsons, O., Levin, D. C., Wright, E., & Hawryluk, G. (1983). Neuropsychological test performance in mildly hypoxemic patients with chronic obstructive pulmonary disease. *Journal of Consulting and Clinical Psychology*, *51*(1), 108–116.

Probst, B., (2015). 'Why This Book Is Needed in', in Prost, B., (1st Ed.) *Critical Thinking in Clinical Assessment and Diagnosis.* Springer, pp. 13-24.

Radvansky G, (2017) *Human Memory*. 3rd Edition. Taylor & Francis.

Raghupathi, W., & Raghupathi, V. (2018). An Empirical Study of Chronic Diseases in the United States: A Visual Analytics Approach. *International journal of environmental research and public health*, 15(3), 431.

Rand, C. S. (2000). "I took the medicine like you told me, doctor": Self-report of adherence with medical regimens. In A. A. Stone, J. S. Turkkan, C. A. Bachrach, J. B. Jobe, H. S. Kurtzman, & V. S. Cain (Eds.), *The science of self-report: Implications for research and practice* (pp. 257-276). Mahwah, NJ, US: Lawrence Erlbaum Associates Publishers.

Redelmeier DA, Dickinson VM. (2012) Judging whether a patient is actually improving: more pitfalls from the science of human perception. *J Gen Intern Med*. 27(9):1195-9.

Redman, T. (2016) Assess Whether You Have a Data Quality Problem. Harvard Business Review. https://hbr.org/2016/07/assess-whether-you-have-a-data-quality-problem.

Rennick JE, Rashotte J. (2009). Psychological outcomes in children following pediatric intensive care unit hospitalization: a systematic review of the research. *J Child Health Care.* 13(2):128-49.

Rice, G. E., & Okun, M. A. (1994). Older readers' processing of medical information that contradicts their beliefs. *Journal of Gerontology*, 49, 119–128.

Robinson, J. A. (1986). Temporal reference systems and autobiographical memory. In D.C. Rubin (Ed.), *Autobiographical memory* (pp. 159-188). Cambridge, England: Cambridge University Press.

Rubin DC. (1982) On the retention function for autobiographical memory. *Journal of Verbal Learning and Verbal Memory*, 21, 21-38.

Rubin, G., George, A., Chinn, D., & Richardson, C. (2003). Errors in general practice: development of an error classification and pilot study of a method for detecting errors. *Quality & Safety in Health Care*, 12(6), 443–447.

Sandler G. (1980). The importance of the history in the medical clinic and the cost of unnecessary tests. *Am Heart J.* 100(6 Pt 1):928-31

Sarkar U., Schillinger D., Bibbins-Domingo K., Nápoles A., Karliner L., Pérez-Stable E.,

(2011) Patient–physicians' information exchange in outpatient cardiac care: Time for a heart to heart? *Patient Education and Counseling*, Volume 85, Issue 2, Pages 173-179.

Schacter, D. L. (1987). Implicit memory: History and current status. *Journal of Experimental Psychology: Learning, Memory, & Cognition*, 13(3), 501–518.

Schacter, D.L. (2001). *The seven sins of memory: How the mind forgets and remembers*. Boston, MA; Houghton Mifflin.

Schank, R. C. (1980), Language and Memory. *Cognitive Science*, 4: 243-284.

Schonfield, D., & Stones, M. J. (1979). Remembering and aging. In J. F. Kihlstrom & F. J. Evans (Eds.), *Functional disorders of memory*. Hillsdale, NJ: Erlbaum.

Schillinger, D., Piette, J., Grumbach, K., Wang, F., Wilson, C., Dahler, C., . . . Bindman, A. B. (2003). Closing the loop: Physician communication with diabetic patients who have low health literacy. *Archives of Internal Medicine*, 163, 83–90.

Sherry, D. F., & Schacter, D. L. (1987). The evolution of multiple memory systems. *Psychological Review*, 94, 439–454.

Smith-DiJulio K, Mitchell ES, Woods NF.(2005). Concordance of retrospective and prospective reporting of menstrual irregularity by women in the menopausal transition. *Climacteric*. 8(4):390-7.

Smith, Wendy B; Safer, Martin A. (1993). Effects of present pain level on recall of chronic pain and medication use. *Pain* Volume 55, Issue 3, Pages 355-361.

Squire, L. (1986) Mechanisms of Memory *Science*, New Series, Vol. 232, No. 4758 pp. 1612-1619.

Strauss, A. and Corbin, J. (1990a), *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*, Sage, Newbury Park, CA.

Terry, W. S. (1988). Everyday forgetting: Data from a diary study. *Psychological Reports*, 62, 299–303.

Tran VT, Montori VM, Eton DT, Baruch D, Falissard B, Ravaud P. (2012) Development and description of measurement properties of an instrument to assess Treatment Burden among patients with multiple chronic conditions. *BMC Med*. 10:68.

Tulving E. (1972). "Episodic and semantic memory," in *Organization and Memory*, Vol. 1972, eds Tulving E., Donaldson W., editors. (New York: Academic Press;), 381–403.

Tulving, E. (1983). *Elements of Episodic Memory*. New York: Oxford University Press.

Tulving, E. (1985). How many memory systems are there? *American Psychologist*, 40, 385–398.

Tulving, E. (2002). Episodic memory: From mind to brain. *Annual Review of Psychology*, 53, 1–25.

Turner, J., & Kelly, B. (2000). Emotional dimensions of chronic disease. *Western Journal of Medicine*, 172(2), 124–128.

Twomey, M., Sammon, D., Nagle, T. and O'Raghallaigh, P. (2018) 'A check list designed to improve memory recall amongst CF patients', *ECIS 2018: Twenty-Sixth European Conference on Information Systems*, Portsmouth, UK, 23-26 June.

Twomey MB, Sammon D, Nagle T (2020) The Tango of Problem Formulation: A Patient's/Researcher's Reflection on an Action Design Research Journey *J Med Internet Res* 22(7): e16916

Vance DE, Farr KF. (2007) Spaced Retrieval for enhancing memory: implications for nursing practice and research. *J Gerontol Nurs.* 2007 Sep;33(9):46-52.

Van Raan, A.F.J. (1996). Advanced bibliometric methods as quantitative core of peer review-based evaluation and foresight exercises. *Sciento-metrics*, 36(3), 397–420.

United Nations (2017). *World Population Prospects: The 2017 Revision, Key Findings and Advance Tables*. https://esa.un.org/unpd/wpp/Publications/Files/WPP2017_KeyFindings.pdf [Last accessed 26/09/2018].

Waldron CA1, van der Weijden T, Ludt S, Gallacher J, Elwyn G. (2011) What are effective strategies to communicate cardiovascular risk information to patients? A systematic review. *Patient Educ Couns*. 82(2):169-81.

Walter, S., & Meier, B. (2014). How important is importance for prospective memory? A review. *Frontiers in Psychology*, 5, 657.

Watson M., Smith A., Watter S. (2005) Leximancer Concept Mapping of Patient Case Studies. In: Khosla R., Howlett R.J., Jain L.C. (eds) *Knowledge-Based Intelligent Information and Engineering Systems.* KES 2005. Lecture Notes in Computer Science, vol 3683. Springer, Berlin, Heidelberg

Webster, J., & Watson, R. (2002). Analyzing the Past to Prepare for the Future: Writing a Literature Review. *MIS Quarterly*, 26(2), Xiii-Xxiii.

World Health Organization. (2016) *Diagnostic Errors: Technical Series on Safer Primary Care*, https://apps.who.int/iris/bitstream/handle/10665/252410/9789241511636-eng.pdf;jsessionid=205337C2D53A8298D47551310C5FA00C [last Accessed 07/07/2020].

World Health Organisation (2017). *Cardiovascular diseases* (Key Facts). http://www.who.int/en/news-room/fact-sheets/detail/cardiovascular-diseases-(cvds) [Site last visited 27/09/2018].

World Health Organization. (2018) *Ageing and health*. https://www.who.int/news-room/fact-sheets/detail/ageing-and-health.

Zhou Q., (2015) Coffee consumption and risk of endometrial cancer: a dose-response meta-analysis of prospective cohort studies. *Scientific Reports*, volume 5, Article number: 13410.

Appendix C

Paper 3: Memory Recall Challenges within the Medical Appointment: A Review of the Literature.

C.1 Abstract

Memory recall/information retrieval of a patient's medical history *within* the medical appointment is highly problematic, reported to be "*flawed, incomplete and erroneous"*. This, despite the importance of medical history to the success of the medical encounter. The purpose of this article is to explore the memory recall/information retrieval challenges reported *within* the context of this complex social environment. Our analysis is set within a systematic literature review, identifying 49 publications that explicitly consider memory recall/information retrieval activities *within* the medical appointment. Rigorous examination was conducted using established open coding techniques, resulting in the identification of 227 concepts which were then (where appropriate) compiled into 63 categories, three of which we have analysed in this paper.

Our results point to the prevalence of three leading patient/carer memory recall/information retrieval challenges (*within* the *elicitation* phase of the medical appointment) reported in the literature over the past 43 years; forgetting, health literacy and emotional state. Hence, the medical community attain a renewed appreciation/understanding vis-à-vis the reasons why patients/carers have such difficulty recalling their medical histories, which is critical to the diagnostic process. Moreover, the study contributes to the sociological and health communities

by bringing into focus the serious ramifications of these challenges to the diagnostic process, and on patient's safety and well-being, highlighting the importance for further consideration/attention to memory recall/information retrieval *within* the medical encounter.

Additionally, the review facilitates a thorough understanding of memory recall/information retrieval and an appointment's success. This comprehension is abstracted into a conceptual model of memory recall/information retrieval in the *elicitation* phase of the medical appointment. The model facilitates an understanding/shared understanding of the memory recall/information retrieval process *within* this complex setting. Furthermore, the review highlights the many research gaps (for many disciplines) that exist *within* this unique medical environment, serving as suggestions for future potential enquiry.

Keywords: Memory recall, Information retrieval, Patient/Carer, Medical, Appointment, Challenges.

C.2 Introduction

Memory is defined as a sophisticated cognitive process that human beings have gained over time through evolutionary development (Shimizu, 2017). The most dominant metaphor for memory is the literacy metaphor (Danziger, 2008), where memory is described as "*encoding, storage, and retrieval, much like writing books and storing them on a shelf"* (Radvansky, 2017, p.6). The prevailing modern version of this is the computer metaphor, which helped propel the cognitive revolution of the mid-twentieth century (Radvansky, 2017).

Considered as perhaps the most fundamental features of human thought, memory lends structure to our existence, it makes us distinct, it furnishes each of us with an appreciation of identity, it is one of the most private features of ourselves and is central to the creation and development of human social relationships, where we swap and share memories from our lives, by way of stories (Radvansky, 2017).

In other social contexts, such as the medical appointment (the main nexus of communication between the patient/carer and the doctor), a medical diagnosis frequently hinges on the patients/carers ability to retrieve information from memory (remembering) and therefore is seen as a key contributor to the successful conclusion of the medical appointment itself, and to the health outcomes of the patient (Cohen et al., 1995).

This paper aspires to contribute to the health, information systems (IS) and sociological communities by augmenting our understanding of the role that memory recall/information retrieval has *within* the medical appointment, specifically within

the *elicitation* phase. The paper examines the progress of research in this area, identifying the gaps in the extant literature, highlighting opportunities for potential enquiry. The investigation is important as it is essential to have a comprehensive understanding of information retrieval *within* the medical appointment, including the challenges or difficulties of memory recall/information retrieval *within* this unique environment and the critical contribution that a thorough understanding of memory recall/information retrieval can make to an appointment's success.

This paper is arranged as follows: Section C.3 presents a brief overview of the medical appointment, individual memory from a sociological perspective, memory *within* the context of medical appointment, and closes with the research question to be considered in this study; Section C.4 describes the research method utilised in performing the literature review, together with the journal selection approach and the data analysis methods applied; Section C.5 explains the examination conducted in our enquiry and the findings of our investigation of memory recall/information retrieval *within* the *elicitation* phase of the medical appointment. We bring our study to a close by summarising our exploration, presenting our conceptual model, making recommendations for future investigations and addressing the limitations of the review.

C.3 Background

C.3.1 The Medical Appointment

Despite the fact that the concept of the medical appointment has been around since the 5th century BCE, it has only become the focus of rigorous investigations on the

part of medical physicians, psychiatrists, and behavioural scientists within recent years (Lazare, 1995). These parties have acknowledged the intricacy and significance of the medical appointment, especially as it has a significant effect on communication, data quality, decision-making, adherence, patient/carer satisfaction, doctor satisfaction, and patient outcomes (Lazare, 1995).

From a communications standpoint the medical appointment can be described as an intricate narrative that details a series of activities and the associations between them (Radvansky, 2017). These narratives must be as clear as possible, going further than a straightforward series of statements, to an illustrative framework affording comprehension of just "*how and why*" proceedings occurred the way they did, whereby the framework consists of objectives, impetuses, deliberations, and feelings that generate a uniquely human quality and setting (Chafe, 1990; Labov, 1982; Linde, 1993).

The most generally recognised purpose of the medical appointment is to establish the class of problem that a patient presents *within* the medical appointment, or to "*make the diagnosis*" (Lazare, 1995). In order to formulate a diagnosis, the doctor must engage in a logical bi-directional conversation with the patient/carer regarding medical history, current well-being, current medication and so on, referred to as the *elicitation* phase (Figure C-1) of the appointment (Sarkar et al., 2011). Research indicates that this medical history provides anything between 60 and 80 percent of the material required by a doctor in order to arrive at an accurate diagnosis (Hampton et al., 1975; Sandler, 1980; Kassirer, 1983).

When the diagnosis has already been ascertained (as in the case of a chronic condition), the appointments objective takes on the form of problem observation, where the doctor keeps a close eye on any deviations in the patient's disease and illness behaviour (Lazare, 1995). However, even where a clinical diagnosis has been made, it is still necessary for the patient/carer to report a medical history, current well-being and current medication at each appointment, as the status of an illness often changes over time (Martin et al., 2014).

In tandem with this, the doctor must also understand the patient's response to his or her illness (which can alter over time) and the degree of management that the patient feels capable of (Lazare, 1995). Additionally, doctors should provide an appropriate level of information to the patient/carer in the *explanatory*/*elucidation* phase of the medical appointment, where the clinician engages in educating the patient/carer in a particular area, for instance a diagnosis, self-management plans or providing recommendations about medication changes and further diagnostic workups (Martin et al., 2014).

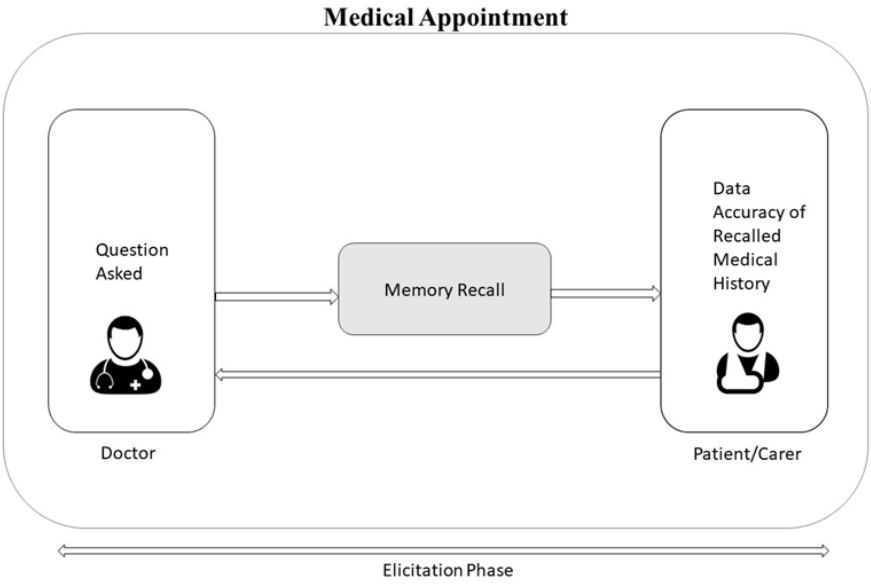


Figure C-1 Elicitation phase of the medical appointment

C.3.2 Individual Memory - A Sociological Perspective

Undoubtedly, our ability to temporally store, maintain and recall information, as required for usage in ensuing goal oriented cognitive endeavours, is a vital skill as we go about our daily lives. "*As long as we live in a human society, we need to regulate our behaviours in pursuit of desirable social and interpersonal goals*" (Maehara, 2017, p40).

Human declarative long-term memory (LTM) can be divided into three main types: working memory, semantic memory, and episodic memory (Appendix J – descriptions declarative LTM types). Working memory is a system for the temporary storage and processing of information required to accomplish cognitive tasks, such as understanding, reasoning, and learning (Nouchi, 2017). Semantic memory on the other hand facilitates the organised chronicling and recall of knowledge and facts that relate to the world around us (Ibid). Whereas Episodic memory is the ability to capture our experiences of specific events. These events taken together make up the building blocks of our Autobiographical memory.

Having taken a deeper cognitive perspective in an earlier paper (Paper 2 - Appendix B), we decided to take a sociological viewpoint in this paper to enrich our understanding/appreciation of the domain. Taking such a multi-discipline approach enriches our comprehension of a problem, advancing our mental models and augments our successes in solving problems (Twomey et al., 2020). Moreover, its facilities new conversations and exposes possible research directions.

The key difference between cultural memory and the biological memory systems of the brain lies in its social roots, especially interactive skills and social

interdependency (Tomasello, 1999). The study of memory from a sociological perspective began to develop systematically in the 1980s stemming from the works by pioneer Maurice Halwachs (between the 1920s and the 1940s) who contested that an individual's memories are etched into cognitive and emotional social frameworks, acting as a scaffold on which the memories are supported and which facilitates meaning (Jedlowski, 2001). Indeed, these very frameworks consist of the mechanisms through which the past is selected, ordered and understood (cf Halbachs, 1925/1994; 1950/1997).

In 1932, Bartlett drew our attention to the social features of an individual's memory arguing that "*Our memories are social to the extent that they codify perceptions on the basis of their meaning, i.e. on the basis of a structure of knowledge of the world which in turn is the expression of the individual's membership of a culture*". (Jedlowski, 2001, p.31). Sociology has focused on memory expressed in narrative rituals (Namer, 1987a) which humans utilise in a variety of social settings especially in autobiographical accounts.

These accounts have a tendency to be organised through the use of temporal references afforded by social setting; social chronologies and personal experiences are intertwined, the degree to which depends on the individual's assimilation into a group or a society as a whole (Cavalli, 1985; De Connick & Godard, 1990). The social aspect of memory becomes quite apparent as we witness such events as a narration through language – a social institution - "*the a priori resource that helps give expression to recall, and narrative discourse necessarily takes place within a social context*" (Jedlowski, 2001, p. 32).

The narrative mechanism in memory recall/information retrieval takes place within a discourse between at least two actors; the narrator and the recipient who listens, processes, records and intervenes by questioning, with an implied understanding between actors that the social rules of dialog are adhered to. Therefore, there is a very social quality to remembering which is connected to the very fabric of the particular relationship in which it takes place (Macioti, 1985).

Sociologists tend to take a constructivist view of individual memory, where memory is not the past itself, but a representation, understood as a social construction by individuals and by communities or social groups (Berger & Luckman, 1966; Bruner, 1991; Jedlowski, 2001). It therefore embodies "*an active reconciliation of past and present. The meaning of the past in relation to the present is what is at stake*" (Keightley, 2010, p.57). Moreover, Sociologists have long acknowledged that past experiences help mould our present identities, behaviours, and outcomes (Shostak & Fox, 2012). "*Through practices of institutionalisation and commemoration, memories of past events become part of the cultural milieu that gives meaning to present events, choices, and identities*" (Shostak & Fox, 2012, p.364; Cunningham et al., 2010).

The sociology of medicine precedes Parsons's (1951) theoretical analysis, with both doctors and social scientists seeking to assess the importance of doctor patient engagements in influencing medical outcomes (Frankel et al., 2003). And so, we turn to memory recall *within* the medical appointment setting.

C.3.3 Memory Recall *Within* the Medical Appointment

In this part of Section C.3, we briefly visit declarative LTM *within* the confines of the medical appointment. Investigations of doctor patient/carer interaction have primarily focused on the extent to which patients/carers can remember clinician explanations or instructions *during* the *elucidation* phase of an appointment, and how this may be improved upon (Ley et al., 1973; Bradshaw et al., 1975). However, the proficiency of patients/carers to recall a medical history in the *elicitation* phase of the medical appointment including health events experienced outside the clinical environment and convey these to the doctor has garnered a much lesser degree of consideration (Cohen et al., 1995).

As an alternative to only considering memory for the *elucidation* phase of medical visits alone, a patient/carer also needs to be able to recall other health-related events that happen between appointments, including illness episodes, symptoms, appointments with other clinicians, treatments, medications and so on (Ibid). These health-related events are all part of a patient's medical history, and include frequencies, dates, durations and severities, which is the "*kind of detailed information a doctor needs in order to make a diagnosis"* (Cohen et al., 1995. p.275).

Unfortunately, as the volume of information to be remembered grows, the percentage of accurate material that is recalled diminishes (McGuire, 1996). Therefore, it is unsurprising that a patients' recall of medical history, is "*very likely to be flawed, incomplete and erroneous*" (Cohen et al., 1995. p.273). Remarkably, even "*maternal memory is not to be relied upon: the underlying tendency is towards*

forgetfulness" (Oakley, 2016, p.534). Perhaps not so astounding is that "*forgetting information about others is a frequent experience*" (Ray et al., 2019, p.259; Young et al., 1985).

Flaws in memory recall have significant health (Martin et al., 2014) and social consequences (Ray et al., 2019). Indeed, the WHO reports that 56% of diagnostic errors *within* the medical appointment are caused by poor medical history (WHO, 2016), many as a result of incomplete and inaccurate information from the patient (Berner & Graber, 2008). Missing or inaccurate information can have several pernicious effects (Redman, 2016), where misdiagnosis and poor decisions often result in patients being subjected to superfluous expensive medical procedures, frequently causing preventable pain and suffering (Personal Injury Team Ireland, 2017). Moreover, a misdiagnosis may bring about a deterioration in a patient's condition, (leading to life-altering consequences), substantial psychological distress/problems and in some cases death (Ibid).

As one may well imagine the use of memory by a patient or carer is both continuous and varied in terms of the time, place, and context during the course of managing an illness. From the perspective of the medical appointment, while one can of course envisage a patient or carer retrieving information from memory *before*, *after* and *between* their medical appointments, the purpose of this study is to identify and categorise the literature that explicitly mentions memory recall/information retrieval and the challenges of same *within* the context of the medical appointment. This is important given how critical memory recall is to the communication of a

patient's medical history, and how significant an input this information is to the diagnostic process.

Memory failure is as relevant today as it was 43 years, most recently, Schoth et al. (2020) reported on memory recall for pain-related information in individuals with chronic pain, whereas Twomey et al. (2020) re-counted the research journey of a Cystic Fibrosis (CF) patient who designed an aid to memory recall/information retrieval for CF patients/carers *within* the medical appointment. Investigating the different perspectives that exist in journal publications will aid our understanding of memory and its role *within* the medical appointment. More specifically, we sought to answer the following research question: *What are the memory recall/information retrieval challenges reported within the context of the medical appointment?* As a result of being able to answer this question we will be able to identify the gaps that exist in the current literature regarding memory recall/information retrieval difficulties *within* the medical appointment, serving as future research prospects. As one may envisage this research holds different significance for the various stakeholders *within* this environment, which we will also examine.

C.4 Method

Our review is systematic and therefore is explicit and reproducible, identifying, evaluating, and synthesizing the existing corpus of work by researchers, scholars, and practitioners (Fink, 2005). A structured approach is also endorsed by Rousseau et al. (2008), who contend that literature reviews be *"comprehensive accumulation, transparent analysis, and reflective interpretation"* (2008, p. 7) of studies endorsed

to a particular question. Hence, we have implemented eight coding steps (Finney & Corbett, 2007; Carley, 1993; Alhassan, 2016) with the aim of carrying out an in-depth analysis of the content in a particular selection of journal publications.

Stage 1: Decide the level of analysis

As outlined in Figure C-2, a total of 39 databases (Appendix M) were searched in February 2018 (and again in August 2018 to check for any new articles) using the keywords of "*memory recall*", "*information retrieval*", "*patient*", "*medical*" and "*appointment*" in either the title or abstract. Of the 1,811 works initially retrieved, 1,395 were disregarded as they focused on human memory disorders (our research focus was on the general/chronic patient population, and not those with cognitive memory disorders). A further 367 were excluded as their content was deemed relevant to a separate area of enquiry, unrelated to the memory recall/information retrieval of patients *within* the medical appointment. On completion of our final analysis in the exclusion/inclusion stage of our review we were left with 49 papers for appraisal (Appendix N).

Stage 2: Decide how many concepts to code for

In stage 2, we elected to use open coding where the information is unravelled into distinct components, thoroughly scanned, checked for any resemblances or variances, coupled with queries regarding the observables discovered in the data (Strauss & Corbin, 1990).

Stage 3: Decide whether to code for the existence or frequency of a concept

In advance of step 3 (in the protocol phase) we had agreed to code for the frequency of concepts rather than just the mere existence of a concept. This approach facilitates the purposeful construction of a descriptive, multi-dimensional preliminary framework for subsequent analysis thereby augmenting the insights gained from the exploration of the literature, making a conversation of relevance and significance conceivable (Finney & Corbett, 2007; Alhassan et al., 2016

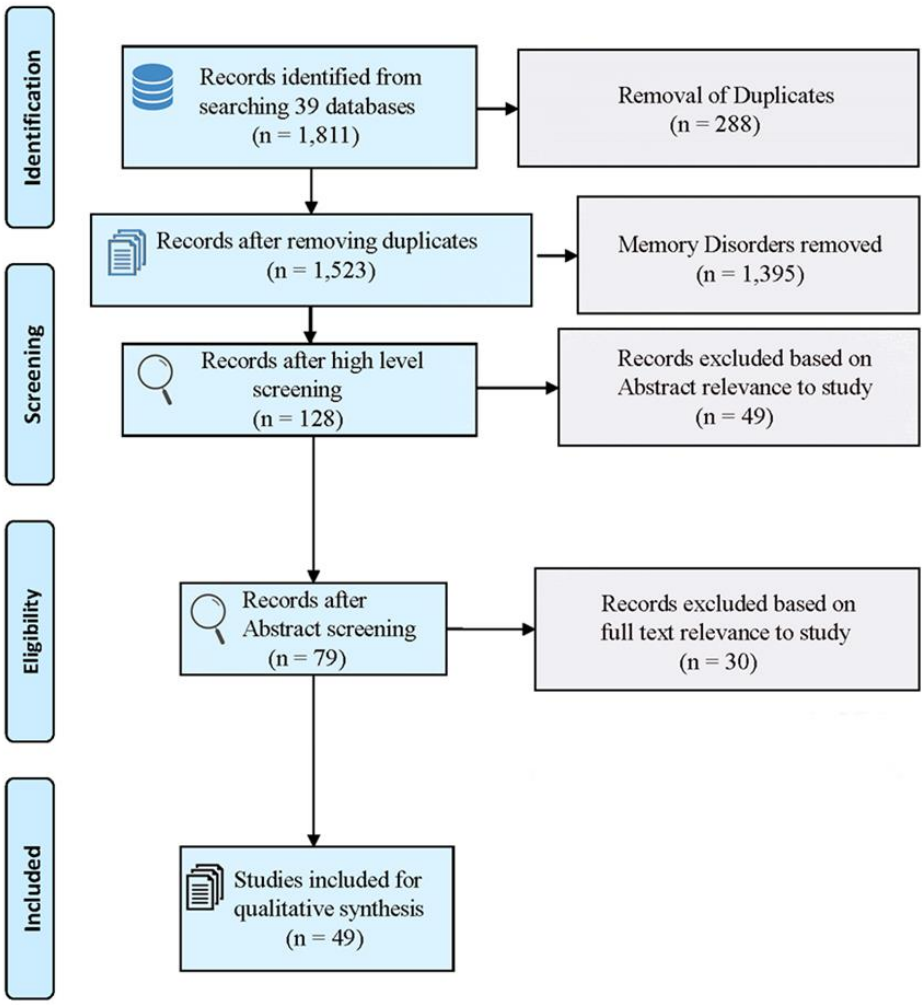


Figure C-2 Review of Literature Flowchart (adapted from Zhou, 2015)

Stage 4: Decide on how you will distinguish between the concepts

This stage is referred to as the level of simplification of expressions where researchers need to make a choice between coding for concepts precisely as revealed or where possible, in another revised or abstracted structure (Finney & Corbett, 2007; Alhassan et al., 2016).). In this paper, one concept, emotional state was emergent, whereas the other two concepts, health literacy and forgetting were pre-existing concepts which we used in our analysis.

Stage 5: Develop rules for coding the text

All included manuscripts were initially subjected to examination with a particular emphasis on detecting references to "*memory recall*". Similar concepts that emerged were then grouped in categories where it was appropriate to do so.

Stage 6: Decide what to do with "irrelevant" information

Following Carley (1993) who advocates the removal of any information that is found to be unrelated to an enquiry, enabling more effective content analysis practices and conceptual refinement, we coded only those aspects of the text that clearly related to memory recall *within* this environment.

Stage 7: Coding the text

We used two analytical techniques to accomplish open coding effectively (Corbin & Strauss, 1990; Glaser, 1992). Firstly, any analogous concepts were collectively grouped together below appropriate higher-order explanatory classifications (Corbin & Strauss, 2008). The second practice used when coding the text involved

scrutinised our data in a line by line manner, compelling us to authenticate and saturate categories, thus moderating the chances of any noteworthy omission/s (Glaser & Holton, 2004).

Stage 8: Analysing the results

The primary method used in the analysis stage involved reviewing the constructs in terms of the frequency and scale to reflect the levels of reporting. That is to say, we created scale levels of: none (no mention of the concept), low (a concept is only touched upon in a paper) and high (a concept is a focus of a paper).

C.5 Analysis & findings

A Microsoft Excel spreadsheet was developed whilst reviewing the 49 selected papers as the before-mentioned open coding analysis was applied iteratively (as per stage 7). We sought to answer the following research question:

What are the memory recall/information retrieval challenges reported within the context of the medical appointment?

As we ascertained earlier, the recall of medical history is "*very likely to be flawed, incomplete and erroneous"* (Cohen et al., 1995, p.273). The knock-on effect of memory recall/information retrieval issues in a medical appointment is profound in terms of the quality of information imparted to a doctor, his/her ability to make an effective diagnosis, decision-making, poor adherence to treatments, all culminating in poor patient outcomes (Cohen et al., 1995). Therefore, we sought to appreciate the frequency of memory retrieval challenge concepts, including the year that the

concepts first appeared in literature. In our research question we investigate the reported challenges or obstacles to memory recall/information retrieval *within* the medical appointment as reported by the literature including Forgetting, Health Literacy and finally Emotional State. Papers not included in our analysis did not touch on or focus upon any of memory recall/information retrieval challenges.

C.5.1 Forgetting

Given the fact that "*40–80% of medical information provided by healthcare practitioners is forgotten immediately*" (Kessels, 2003, p.219), we first decided to look at the challenge of forgetting or lost information or the inability to retrieve material learnt earlier. Tulving (1974, p.74) describes forgetting as "*… the inability to recall something now that could be recalled on an earlier occasion*". As one would expect memory and forgetting are closely interlinked. Our understanding of forgetting has advanced considerably since Ebbinghaus (1885) first depicted forgetting as a logarithmic function in his Learning Curve/Forgetting Curve. Since then, a number of theories portraying forgetting in relation to different modes of "*interference*" have gained strong empirical endorsement, where *"interference*" can be "*proactive*" or "*retroactive*" in nature depending on the amount of information to be remembered (Della Sala, 2010). Additional hypotheses regarding the process of recall (where opposing or comparable cues disturb memory recall/information retrieval) and "*reconsolidation*" (the retrieval of data in response to a memory trace) have also garnered support (Ibid).

In an effort to see beyond the concept of forgetting in its most simplistic form and to really understand the challenge as reported by the literature, we display our

analysis in Table C-2, which looks through the lens of Schacter's (1999) seminal paper "*The Seven Sins of Memory*" in which he depicts forgetting as seven sins (Table C-1).

Table C-1 The Seven Sins of Memory (adapted from Schacter, 1999)

Sin	Description
Transience	Memories for facts and events are forgotten over time. First reflected in the "*forgetting curve"* by Ebbinghaus (1885).
Absent-Mindedness	Absent-mindedness happens when information is not encoded correctly when information is first presented due to attention been focused elsewhere.
Blocking	When people have difficulty retrieving a desired memory because other memories are obstructing access.
Misattribution	Misattribution occurs when one can remember something but misattribute to an incorrect time, place or person.
Suggestibility	Suggestibility occurs when new/altered memories are provided by outside sources, possibly causing correct information to be forgotten or distorted.
Bias	Bias can occur when memories are altered by what one already known, believes or expects. Memories can also be changed by one's current mood and emotional state.
Persistence	Persistence in memory is compromised by knowledge that should be forgotten or information that one would prefer to forget.

The results quite clearly show that transience is the leading concept under the forgetting classification that appears in the reviewed material. This aids our understanding of why memory for medical history is "*often flawed, incomplete and erroneous"* (Cohen et al., 1995, p.273). It also augments our appreciation of the contribution that transience makes to the declarative long-term memory issues such as Episodic memory and Autobiographical memory (Appendix J - description of declarative LTM types). Thankfully, transience can sometimes be overcome with cues and hints provided *during* a conversation which can prompt the retrieval of memories that appear to have been forgotten (Tulving & Pearlstone, 1966; Koutstaal & Schacter, 1997).

Table C-2 shows that absentmindedness as a forgetting concept has been a focus of research three times (first in 1979); this is somewhat surprising given the fact that the medical appointment by its very nature is often a very stressful event for the patient/carer (Turner, 2000). Therefore, the ability to give adequate attention for sufficient encoding or retrieval of information is often difficult (Kessels, 2003). To appreciate this, visualise a young mother with an upset baby at a medical appointment who endeavours to absorb what the doctor is imparting while trying to comfort her child. The frequency of absentmindedness is also surprising given the potentially harmful consequences of forgetting to perform a particular action, referred to as absent-minded errors of Prospective memory. There are many instances of this type of forgetting in daily life; to give an illustration from a medical appointment perspective, we see Prospective memory failure ranging from forgetting to turn up at medical appointments, to forgetting to ask the clinician questions regarding symptoms (or other issues that may be causing concern), to

forgetting to take one's medication as advised/agreed *within* the medical appointment (Martin et al., 2014).

What is also of interest is the lack of research regarding misattribution as a type of forgetting, especially when one considers the prevalence of research in Episodic memory. Rubin et al., (2015) report that the details of similar frequent events can often seem to almost merge into one another. Therefore, we would have expected more reports of misattribution, given the recurrent nature of visits to a doctor for chronic patients, and hence the difficulty of trying to separate out the intrinsic details of these very similar events.

Not surprising is the lack of papers referencing suggestibility, as doctors obviously never intend on providing information that may disrupt the recall of information from patients. On the contrary the doctor's intention is to elicit accurate information in order to facilitate an accurate diagnosis.

Table C-2 ***Frequency of forgetting concepts (adapted from Schacter's Seven Sins of Memory, 1999)*** *– those in grey text are when a concept is just touched upon*

Decade		1975-1985	1986-1996	1997-2007	2008-2018	Focus	Touched Upon
Sins Of Memory							
Forgetting	**Transience**		(Dinges et al., 1992); (Grubb et al., 1996)	(Albert et al., 1999); (Drysdale et al., 2000); (Grubb et al., 2000); (Rand et al., 2000); (Crews et al., 2001); (Brown et al., 2002); (Keeble et al., 2002); (Bird et al., 2004); (Vance et al., 2007); (Jessen et al., 2007); (Matheis et al., 2007)	(Jansen et al., 2008); (Posma et al., 2009); (Kaufman et al., 2009); (Pressler et al., 2011); (Mc Kinstry et al., 2011); (Labban et al., 2011); (Redelmeier et al., 2012); (Misra et al., 2013); (Hanon et al., 2014); (Jones et al., 2015); (Meeusen et al., 2015); (Brick et al., 2016); (Lipson-Smith et al., 2018)	**8**	**18**
	Absentmindedness	(Crook et al., 1979)		(Hufford et al., 2003)	(Holman et al., 2010); (Ahn et al., 2017)	**3**	**1**
	Blocking					**0**	**0**
	Misattribution	(Schank et al., 1980)		(Crews et al., 2001);	(Rennick et al., 2009)	**0**	**3**
	Suggestibility						
	Bias		(Huttenlocher et al., 1990); (Smith et al., 1993); (Homendes et al., 1994);	(Rand et al., 2000); (Hufford et al., 2003); (Smith -DiJulio et al., 2005)	(Hoppe et al., 2008); (Kaufman et al., 2009); (Redelmeier et al., 2012); (Misra et al., 2013);	**6**	**4**
	Persistence					**0**	**0**

The number of papers with bias as a form of forgetting is notable but not altogether unexpected given that "*social desirability and memory biases can lead to ceiling effects in self-report scales where an unrealistic majority of respondents indicate perfect adherence"* (Stirratt et al., 2015, p.471). The volume of research into this form of bias is not that difficult to understand given the fact that non-adherence results in annual costings ranging from "*US$100 to U$290 billion in the USA, €1.25 billion in Europe and approximately $A7 billion in Australia*" (Cutler, 2018, p.1). These figures illustrate the gravity of the situation, hence the push in research to try and understand, and ameliorate, the issue.

We see that Prospective memory too can fall victim to bias in the form of overconfidence or "*projection bias*" (Loewenstein, O'Donoghue & Rabin, 2003); this is similar to other forms of information projection such as "*hindsight bias*" and "*curse of knowledge*". That is, patients/carers project their present memory state onto all future periods and evolve their expectations for future recall and behaviour accordingly, this can result in the already discussed consequences of Prospective memory and forgetting (Ibid). Persistent memory as a concept will be discussed later under emotional state below, we now move onto health literacy.

C.5.2 Health Literacy

Defined by the World Health Organization (WHO, 2009) as: "*the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health"*, we next analysed this concept in the context of a challenge to information retrieval *within* the medical appointment (Table C-3).

Table C-3 ***Frequency of health literacy concept*** *– those in grey text are when a concept is just touched upon*

Decade	1975-1985	1986-1996	1997-2007	2008-2018		
Challenge					Focus	Touched Upon
Health Literacy	(Schank et al., 1980)		(Rand et al., 2000); (Brown et al., 2002); (Keeble et al., 2002); (Hufford et al., 2003); (Bird et al., 2004); (Vance et al., 2007); (Matheis et al., 2007);	(Jansen et al., 2008); (Ferguson et al., 2008); (Posma et al., 2009); (Kaufman et al., 2009); (Pressler et al., 2011); (Redelmeier et al., 2012); (Misra et al., 2013); (Amin et al., 2013); (Hanon et al., 2014): (Jones et al., 2015); (Meeusen et al., 2015); (Ahn et al., 2017); (Lipson-Smith et al., 2018)	10	11

According to Santos et al. (2017) health literacy develops through three sequential stages. The first stage is functional, and concerns the successful communication of information (Nutbeam, 2000). The second stage is collaborative and pertains to proficiency of particular individual skills. The final stage involves a type of critical knowing when and how to use information (Santos, 2017).

As we can see in Table C-3 health literacy as a concept has grown in prevalence over the last three decades with 10 papers giving attention to this concept, this is due to a number of reasons which we will briefly discuss. Low health literacy is reported to be widespread in the public at large, particularly in those with chronic disease/s, with one-third of the adult populace in United States (upwards of 75 million adults) having inadequate health literacy (Kutner et al., 2006).

Health literacy challenges are not always obvious, with patients not always fitting a typical demographic (Weiss & Coyne, 1997). However, the most reliable predictors are a patients/carers age, education, ethnicity, and income (Paasche-

Orlow et al., 2005). In contrast to individuals with sufficient health literacy, those with poor health literacy often exhibit an inferior health status and clinical outcomes (Bennett et al., 1998; Kalichman & Rompa, 2000; Schillinger et al., 2002; Dewalt et al., 2004), poorer self-reported health status (Baker et al., 1997), elevated frequencies of several chronic illnesses (Sudore et al., 2006), lower use of preventative health services (Scott et al., 2002), augmented rates of avoidable hospitalisations and ER visits (Baker et al., 2002; Hardie et al., 2011) and higher death rates (Sudore et al., 2006; Baker et al., 2008). Moreover, people with inadequate health literacy have a tendency to pose less questions to clinicians and so are given less information in medical encounters (Lincoln et al., 2017), further hampering the patient's capabilities to be complete participants in their own care (Baker et al., 1996).

From an information retrieval perspective or challenge to memory recall/information retrieval, when a doctor and patient/carer engage in dialogue it requires complex cognitive processing capacity (Morrow et al., 1992). Any capacity issues on the side of the patient/carer constrains effective comprehension, resulting in an inability to hold onto fundamental concepts so that they are readily accessible for integration into parlance (Kintsch, 1998). General knowledge and field-specific knowledge (for instance health knowledge) support these processes and are accumulated in Semantic memory, (Ibid).

Interestingly, Semantic memory only appeared 4 times (in the 49 papers) as a concept touched upon in despite its importance in health literacy. In Ley's (1988) "*model of health communication*", he maintains that health literacy is a key

ingredient to understanding health information, engaging in dialogue at a medical appointment, and is also vital to recalling such information. Logically, if a patient or carer has low health literacy, they often fail to understand many fundamental aspects of what is being conveyed to them *during* a medical appointment, which impacts directly on communication *within* the appointment and hence also on their ability to recall information effectively (Martin et al., 2014). In other words, if a patient/carer does not understand what a doctor is asking them, how can they form an accurate response to the doctors' question? Moreover, if a patient/carer does not comprehend what is being discussed in a medical appointment (due to poor health literacy) how can they possibly remember or encode the pertinent details of the conversation correctly, so that they can recall them afterwards? Interesting, Lutfey and Freese (2005) point out, that what may be clinically misinterpreted as poor adherence due to poor motivation, may in actual fact be practically explained as limited literacy, with consequential impacts on treatment regimens advised by doctors (Lincoln et al., 2017).

In 2004, Nielsen-Bohlman et al. conducted a review in excess of 300 investigations which indicates how poor patients/carers are at understanding health information that is shared with them. In tandem with this, reports show that physicians are poor at identifying their patients' health literacy level and often misjudge this aspect of a patient's competencies (Seligman et al., 2005). Persons with low health literacy may often conceal their deficits from doctors, from family members and friends because of a sense of shame and awkwardness (Baker et al., 1996; Parikh et al., 1996). The upshot of this form of concealment can be both psychological and physical, consisting of augmented degrees of anxiety, depression, and physical

symptoms (Larson & Chastain, 1990; Link & Phelan, 2006; Lincoln et al., 2017). Furthermore, "*Shame confounds making one's way successfully through the mental health care system. It forecloses needed care, impairs participation in important logistical activities such as completing medical forms and following instructions, and (if experience in consumer research is any guide) sometimes poses an insurmountable barrier"* (Lincoln et al., 2017, p.123).

Individuals with adequate health literacy can face limitations in their health literacy skills during times of illness and stress (Martin et al., 2014). Attempts to identify poor health literacy such as when clinicians check patients' recall have been shown to influence outcomes, but unfortunately this appraisal is often neglected (Bartlett et al., 1984; Schillinger et al., 2003). This is interesting as reports have established how crucial health literacy is to improving patient/carer satisfaction (Cameron, 1996) and augmenting patient/carer disease management (Coates et al., 1996).

C.5.3 Emotional state

Hippocrates, the father of Western medicine, famously noted *"it is far more important to know what person the disease has, than what disease the person has"* (US Medicine, 2013). With this in mind we consider our final memory recall/information retrieval challenge analysed in the context of the medical appointment, that of emotional state (Table C-4). Of note in our research is the prevalence of psychological/neuropsychological, depression, stress, and anxiety as emotional state concepts. This is understandable given the extent that patients with chronic conditions often have to alter their lifestyles, ambitions and career, where many mourn regarding their illness situation before acclimatising to it (Turner,

2000). Moreover, illness can interfere in key aspects of identity, together with embodiment, social roles, and relationships (Bury, 1982; Iphofen, 1999). A shared illness identity frequently transpires where '*individuals, through the illness identity acquired as a result of their illness condition, develop a ''cognitive, moral, and emotional connection'' with other illness sufferers'* (Brown et al., 2004, p.60). Others experience protracted periods of distress and may develop psychiatric disorders, very often in the form of depression or anxiety (Ibid). Therefore, it is understandable why doctors, researchers and society wish to understand the effects of emotional states on cognitive abilities such as memory recall/information retrieval *within* the medical appointment (we note the upward trend in research from 1997 onwards).

According to Schwabe and Wolf (2010) emotional responses that are immediately induced could be to blame for deficiencies in information retrieval by patients. The "*attentional narrowing*" hypothesis proposes that elevated emotional stimulus bought about by a poignant experience necessitates an augmented level of attention, which reduces available attention capacity for information perceived as more minor in significance (Christianson, 1992; Kessels, 2003). As a result, essential information associated with the cause of the arousal, is often better recalled compared with supplementary material surrounding the emotive episode, that is auxiliary in nature (Ibid).

Table C-4 ***Frequency of emotional state concepts*** *– those in grey are when a concept is just touched upon.*

Decade		1975-1985	1986-1996	1997-2007	2008-2018	Focus	Touched Upon
Emotional State	Depresssion		(Grubb et al., 1996);	(Crews et al., 2001): (Albert et al., 2003); (Hufford et al., 2003); (Elzinga et al., 2005); (Jessen et al., 2007)	(Jansen et al., 2008); (Pressler et al., 2011); (McKinstry et al., 2011); (Hanon et al., 2014); (Jones et al., 2015)	5	6
	Stress		(Smith et al., 1993); (Grubb et al., 1996);	(Crews et al., 2001): (Ball et al., 2001); (Elzinga et al., 2005)	(Jansen et al., 2008); (Rennick et al., 2009); (Meeusen et al., 2015)	4	4
	Anxiety	(McKinlay et al., 1975)	(Grubb et al., 1996);	(Ball et al., 2001); (Hufford et al., 2003)	(Jansen et al., 2008); (Rennick et al., 2009); (Posma et al., 2009); (Kaufman et al., 2009); (McKinstry et al., 2011); (Misra et al., 2013); (Amin et al., 2013); (Meeusen et al., 2015)	2	10
	Unease				(Meeusen et al., 2015)	0	1
	Worry				(Waldron et al., 2011); (Misra et al., 2013); (Ahn et al., 2017)	0	3
	Trauma				(Rennick et al., 2009)	1	0
	Resentment			(Crews et al., 2001)		1	0
	Pain		(Smith et al., 1993);	(Hufford et al., 2003)	(Rennick et al., 2009); (Misra et al., 2013)	1	3
	Tension			(Crews et al., 2001)		0	1
	Embarrassment				(Misra et al., 2013)	0	1
	Hopeful				(Jansen et al., 2008)	0	1
	Fear				(Jansen et al., 2008); (Rennick et al., 2009)	1	1
	White Coat Hypertension			(Hufford et al., 2003)		0	1
	Frustration			(Vance et al., 2007)	(Amin et al., 2013)	0	2
	Hysteria			(Crews et al., 2001)		1	0
	Psychological /Neuropsychological			(Albert et al., 1999): (Drysdale et al., 2000); (Grubb et al., 2000); (Rand et al., 2000); (Crews et al., 2001); (Matheis et al., 2007)		5	1

A substantial quantity of literature (regarding the recollections of particular autobiographical episodes) supports that well-being is connected to a person's ability to construct emotionally comprehensible narratives of particular high-stress events (Frattaroli, 2006; Pennebaker & Chung, 2007). More specifically, those that are capable of constructing explanatory accounts, which integrate and resolve emotional events, are later known to exhibit augmented degrees of self-reporting, display higher levels of wellness, coupled with better physical well-being (as

documented via medical appointments), immune system function, and improvements in beneficial behaviours (Frattaroli, 2006; Pennebaker & Chung, 2007). Furthermore, patients capable of constructing a narrative of their life, portraying its trials and stresses as both opportunities and stimuli for self-development, show elevated degrees of accomplishment as young adults (McLean & Breen, 2009), a need to guide younger people, higher levels of emotional stability as middle-aged individuals (Burton & King 2004, McAdams, 2004), often bringing about a spirit of rectitude and tolerance as senior citizens (Webster, 2001). Clearly, our memories and our health are entwined, moulding and shaping each other throughout our lives.

Perhaps unsurprisingly, emotional state also influences frequency judgements of the occurrence of events which are often "*inflated by inclusion of the times the event was mentally reviewed"* (Cohen et al., 1995. p.274) or thought about. Thus, an individual who frequently reflects about a health-related episode (such as a patient who is worried about the flare up of a particular symptom) "*would be more likely to overestimate the frequency with which it occurred and this suggests a possible link between anxiety and accuracy of recall*" (Ibid). Means and Loftus (1991) report the effects that recurrent medical appointments (very common with patient with a chronic condition) have on memory recall/information retrieval, where appointments seem to be represented as an amalgamated generic recollection, particularly if the appointments pertained to less important incidents as opposed to major ones. On the other hand, episodes that are deemed more acute have a greater possibility of being remembered compared with those regarded as less important,

but patients/carers who had experienced a myriad of health-related events nevertheless remembered less about them (Cohen et al., 1995).

What is somewhat unexpected is the frequency of other emotional state concepts such as worry, tension, hope, pain, and fear. This of course may be because these forms of emotional states are too similar in nature to the more frequently reported concepts, it could of course also be that depression, stress and anxiety are simply more significant in terms of their effects on patients and therefore have secured a greater research focus. Nevertheless, we would expect chronic pain to feature more frequently given the way in which it manifests itself, especially in regard to chronic pain, which is known to vary in severity through time and therefore can have extreme effects on a patient's ability to recollect error free (Hunter et al., 1979; Linton & Gotestam, 1983; Roche & Gigsbers, 1986; Norvell et al., 1987; Erskine et al., 1990). Furthermore, it is well recognised that pain can be extremely arduous to convey and to convert into meaningful language (Bourke, 2014; Kugelmann, 1999; Werner & Malterud, 2003; Tarr et al., 2018), especially in the medical encounter, which remains beset with a myriad of misapprehensions (Kenny, 2004; Toye et al., 2013; Tarr et al., 2018).

Trauma (a deeply distressing or disturbing experience) as a concept appears once in the literature, yet we would expect this to appear more often given the very upsetting experiences that some patients/carers have had, resulting in negative spontaneous memories, referred to by Schacter (1999) as persistence (note this forgetting concept did not appear in Table C-2). As one can imagine these flashbacks can be quite unrelenting (Berntsen, 2001), quite realistic (Alexander et

al., 2005), even after a significant timeframe (Porter & Peace, 2007). Moreover, efforts such as "*directed forgetting*" that attempt to halt the recall of an unpleasant experience may actually have the opposite effect of making the memory more prominent, thereby intensifying the undesirable emotional reaction to the memory (Dalgleish et al., 2008). Emotional forgetting has been proposed to be helpful and adaptive for emotion regulation, keeping us from focusing on previous experiences that may cause our emotions to fluctuate to extremes, thereby helping us to be more optimistic and forbearing (Nørby et al., 2015).

We conclude our research question by proposing the relevance of our investigation to our three core stakeholders (the academic, the doctor and the patient/carer) in Table C-5. For the academic certain questions remain to be answered, for example what are the connections between the different types of LTM and subsequent memory recall/information retrieval challenges and how does this affect the overall process of memory recall/information retrieval? To what extent does an individuals' (doctor, patient, and carer) behaviour impact on memory recall/information retrieval and the accuracy of medical history communicated? What role do IS researchers have in addressing the challenges of memory recall/information retrieval in the *elicitation* phase of the medical appointment? How might they help to improve the data quality issues identified herein? How might those in decision systems be involved in aiding the diagnostic process *within* the medical appointment? Do the IS community know all they need to know, so that they can design suitable solution/s to address the issue of poor memory recall *within* the medical appointment? Many questions still remain unanswered.

Table C-5 Summary of Potential Stakeholder Impacts

	Academic	Doctor	Patient/Carer
Research Question	**Inform** The review exposes the challenges to information retrieval *within* this medical environment, including *"forgetting", "health literacy*" and "*emotional state*". However, researchers may wonder if this is a complete set of challenges, or whether others are yet to be identified and explored? Another question that arises out of our analysis is what is the real extent of the various types of forgetting that have not being explored comprehensively for example "*misattribution*" and "*absentmindedness*"? One may also ask why doctors do not address their approach to the *elicitation* phase, given the reports that attempts to address memory recall issues by clinicians have shown to influence outcomes (Bartlett et al., 1984; Schillinger et al., 2003)? More especially given the importance of medical history accuracy to the diagnostic process, and to appointment outcomes. Researchers may ponder as to want associations exists between the various types of LTM, the information retrieval issues reported, and indeed, how IS may address the challenges to memory recall and improve the data accuracy/quality of medical histories.	**Influence** A greater understanding of the various challenges to information retrieval for patients or carers, such as "*forgetting"," health literacy*" and "*emotional states*" and their considerable impacts. For example, our review highlights how poor doctors are at identifying their patients' health literacy levels, in tandem with, how often a patient's health literacy levels are overestimated (Seligman et al., 2005), and the impacts that same has on clinical outcomes (Bennett et al., 1998; Kalichman & Rompa, 2000; Schillinger et al., 2002; Dewalt et al., 2004), elevated frequencies of many chronic conditions (Sudore et al., 2006), and greater mortality rates (Sudore et al., 2006; Baker et al., 2008). This may well result in the medical community rethinking their approach to the *elicitation* phase *within* the appointment, more especially since attempts to address memory recall issues by clinicians in the past have shown to influence outcomes (Bartlett et al., 1984; Schillinger et al., 2003).	**Awareness** Patients/carers gain an awareness of how much information they actually forget, and how quickly they can forget it, where 40–80% of medical information imparted by doctors is forgotten immediately (Kessels, 2003). A realisation of the various types of forgetting that challenge memory recall, and the bearing that a failure to recall has on the medical appointment outcome. They also come to appreciate the effects of their emotional reactions Schwabe & Wolf (2010) and biases (overconfidence or projection bias (Loewenstein, O 'Donoghue and Rabin 2003)) can have on the retrieval of information. Of course, the knowledge that transience can sometimes be overcome with cues and hints provided *during* a conversation (Tulving & Pearlstone, 1966; Koutstaal & Schacter, 1997) may result in behavioural changes in the *elicitation* phase of the appointment.

The doctor on the other hand gains a more comprehensive understanding of the memory recall/information retrieval challenges that must be overcome in order to improve data accuracy *within* the medical appointment. The medical community also comes to comprehend that doctors need help in recognising poor health literacy more effectively, and that they may also need assistance in how they approach eliciting medical histories from patients/carers. For instance, training on techniques or strategies that aid memory recall/information retrieval such as cues, hints or indeed testing patients recall, all of which have been found to aid memory recall/information retrieval (Tulving & Pearlstone, 1966; Koutstaal & Schacter, 1997).

Finally, for patients/carers there is an increased awareness of how much information they actually forget, how quickly they can forget it, together with a consciousness of the various challenges that exist which directly and indirectly effects their capability to remember information accurately and also impacts the outcomes of their medical appointments. Of course, the knowledge that forgetting can be ameliorated with changes in approach to the *elicitation* phase of the appointment such as cues and hints provided *during* a conversation (Tulving & Pearlstone, 1966; Koutstaal & Schacter, 1997) is also of interest to the patient/carer. So too is the realisation that improvements in health literacy may not just affect their ability to recall information but also may also improve clinical outcomes (Bennett et al., 1998; Kalichman & Rompa, 2000; Schillinger et al., 2002; Dewalt et al., 2004), help avoid unnecessary hospitalisations and visits to the emergency department (Baker et al., 2002; Hardie et al., 2011). The outcomes of this awareness may lead to new conversations with their doctor or novel behaviours to try and

remedy or reduce such memory recall/information retrieval challenges. Perhaps, more patients like such the CF patient in Twomey et al., (2018/2020), will be inspired to become the innovators/designers of the future, helping to resolved the challenges of memory recall/information retrieval *within* the medical appointment.

C.6 Summary & Concluding Remarks

Effective communication between a doctor and patient/carer is central to the medical appointment process, where the core function is establishing a correct diagnosis via information that is precise, timely and relevant. Therefore, a key component to successful communication *within* this medical environment is the ability of the patient/carer to retrieve accurate information from their long-term memory *within* the *elicitation* phase of the medical appointment.

Using a systematic approach to the literature review we adopted (c.f. Finney & Corbett's, 2007; Alhassan et al., 2016) an eight-step process, with the initial selection activity returning 1,811 papers. Following rigorous selection and exclusion criteria, 49 papers were found to serve the research objective. These papers were then put through an in-depth content analysis using an open coding analysis technique.

The exploration identifies and explores three memory recall/information retrieval challenges *within* the complex setting of the medical appointment: forgetting, health literacy and patient/carer emotional states. Moreover, it contributes to the sociological and health communities by bringing into focus the serious ramifications of these challenges to the diagnostic process, and on patient's safety

and well-being, highlighting the importance for further consideration/attention to memory recall/information retrieval *within* the medical encounter. Furthermore, the medical community (many of whom experience the arduous task of formulating a diagnosis with poor quality medical history on a day-to-day basis), attain a renewed appreciation/understanding of the many challenges that need to be overcome, in order to improve the quality of medical history data. Perhaps then, this knowledge will serve to ignite a new agenda, where new systems/methods of approaching the *elicitation* of medical histories are explored/developed and utilised by clinicians.

Additionally, the review facilitates a thorough understanding of memory recall/information retrieval and an appointment's success. To this end we have conceptualised our research by creating a model of the *elicitation* phase of the medical appointment process in Figure C-3. This model is akin to Figure C-1 but shows the advancement of our knowledge on completion of our exploration. The model not only serves as an aid to the comprehension of the *elicitation* phase, it also provokes further thought, raising a number of questions, for example, do we know enough regarding the relationships that exist between declarative LTM (and its components) and the memory recall/information retrieval challenges that exist *within* this clinical encounter between doctor and patient/carer? Do we comprehend the intricacies of the recall/communicative process *within* the medical appointment well enough, to be then able to create innovative solutions to improve the data accuracy of medical history remembered and conveyed to doctors, thereby improving diagnosis and patient outcomes? These queries in themselves serve as suggestions for future potential enquiry, many of which will be relevant to the IS community. For example, what role does IS have in advancing/addressing the data

quality issue identified in this review? Do those who specialise in decision systems, have a role to play in resolving the diagnostic process/issue discussed? How might the IS community design a suitable solution/s to address the issue of poor memory recall *within* the medical appointment? As one can see, many questions still remain, providing a rich tapestry of latent enquiry.

Our research has three key limitations. Firstly, the initial search emphasis was only conducted on peer reviewed academic journals in the area of memory recall/information retrieval *within* the medical appointment. This may well have excluded publications in books or websites articles that may have enriched the review further. Also, as previously mentioned there are other areas/environs that are outside the confines of our search criteria (*within* the medical appointment) that may enhance our comprehension of patient/carer memory recall/information retrieval *within* the medical appointment.

This may of course be true, only future research will show if this is the case; therefore, the review highlights three other possible areas for future research; that of patient/carer memory recall/information retrieval *before, after* and *between* medical appointments. Secondly, it could be argued that our search criteria are too narrow, and that we may be missing some seminal papers in the review. However, in counterpoint to this, we have searched 39 databases, crossing the divides of many disciplines to obtain as holistic a view of the literature as possible. Thirdly, there is a lack of insight regarding the current solutions that address the memory recall/information retrieval challenges *within* the context of the medical appointment. It is important to analyse these antidotes to poor memory

recall/information retrieval, and to consider their utility, usability, and robustness, and so this also presents opportunity for further investigation.

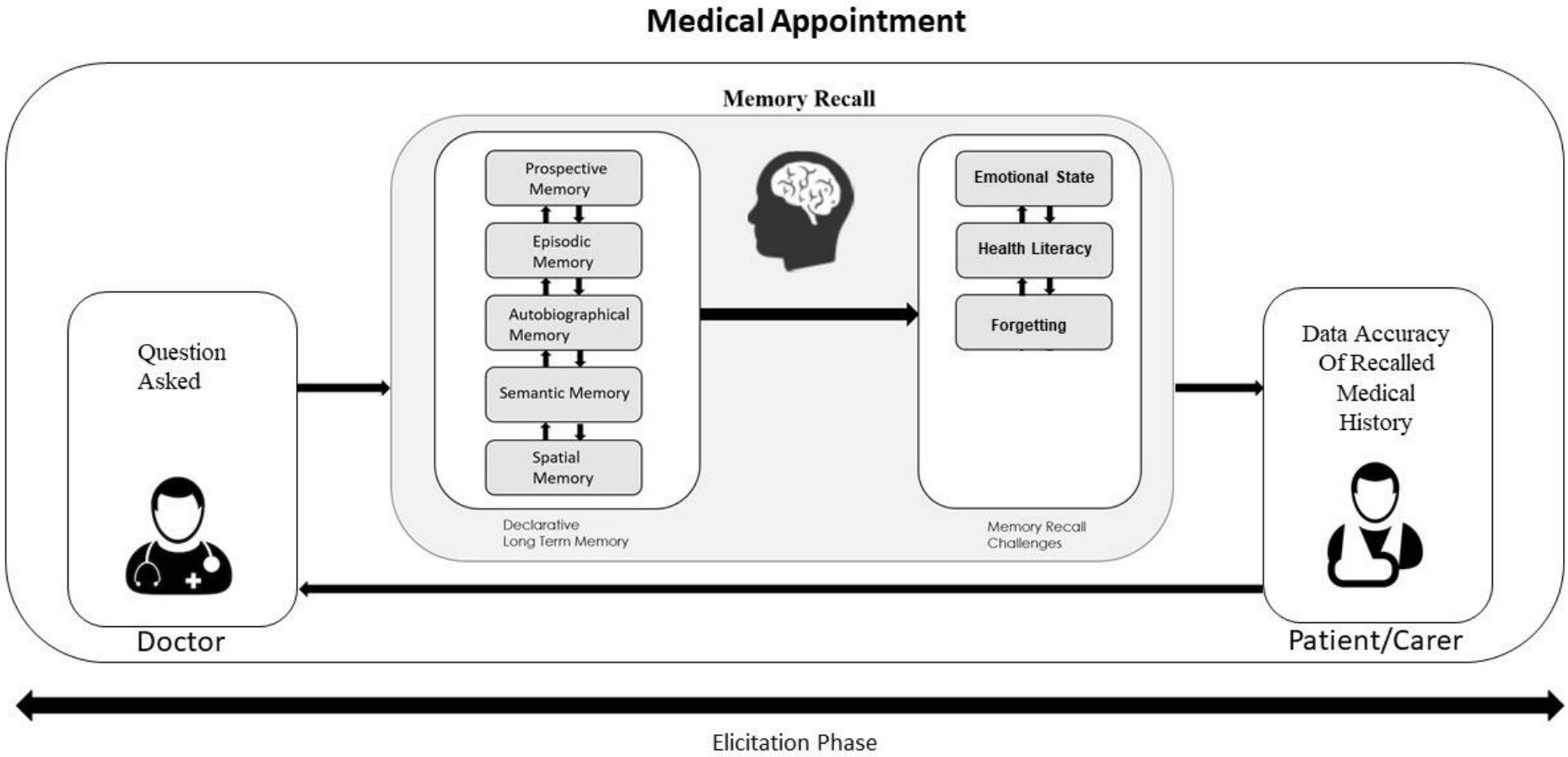


Figure C-3 Elicitation phase of the medical appointment

In summation, there is a genuine necessity for the memory recall/information retrieval process *within* the medical appointment to be more fully comprehended, to be further examined in order to augment our understanding of the dynamics at play in this social environment, leaving behind myopic positions, where we must now observe memory recall/information retrieval *within* the medical appointment through new lenses, bringing fresh perspectives, novel opportunities, contributions to knowledge and innovative solutions to those who toil against the burden of living with a chronic disease and the challenges of memory recall/information retrieval.

C.7 References

Ahn CS., Culp L., Huang WW., Davis SA., Feldman SR., (2017) Adherence in dermatology. *J Dermatolog Treat*. 28(2):94-103.

Albert, S.M., Weber, C.M., Todak, G., Polanco, C., Ronda, C., McElhiney, R., Rabkin, J., Stern, Y., Marder, K. (1999) An Observed Performance Test of Medication Management Ability in HIV: Relation to Neuropsychological Status and Medication Adherence Outcomes. *AIDS Behav*. 3: 121.

Albert, Steven M; Flater, Susanne R; Clouse, Ronda; Todak, George; Stern, Yaakov; Marder, Karen. (2003). Medication Management Skill in HIV: I. Evidence for Adaptation of Medication Management Strategies in People with Cognitive Impairment. II. Evidence for a Pervasive Lay Model of Medication Efficacy. *AIDS and Behaviour,* Volume 7, Issue 3.

Alexander, K. W., Quas, J. A., Goodman, G. S. Ghetti, S., Edelstein, R. S., Redlich, A. D., Cordon, I. M., & Jones, D. P. H. (2005). Traumatic impact predicts long-term memory for documented child sexual abuse. *Psychological Science*, 16, 33– 40.

Alhassan, I., Sammon, D., Daly, M., (2016) Data governance activities: an analysis of the literature, *Journal of Decision Systems*, 25:sup1, 64-75.

Amin H, Malik AS. (2013) Human memory retention and recall processes. A review of EEG and fMRI studies. *Neurosciences* (Riyadh). 18(4):330-44.

Baddeley, Alan; Wilson, Barbara (1988). Comprehension and working memory: A single case neuropsychological study. *Journal of Memory and Language*, Volume 27, Issue 5.

Baker, D. W., Parker, R. M., Williams, M. V., Pitkin, K., Parikh, N. S., Coates, W., & Imara, M. (1996). The health care experience of patients with low literacy. *Archives of Family Medicine,* 5 (6), 329–334.

Baker, D. W., Parker, R. M., Williams, M. V., Clark, W. S., & Nurss, J. (1997). The relationship of patient reading ability to self-reported health and use of health services. *American Journal of Public Health*, 87 (6), 1027–1030.

Baker, D. W., Gazmararian, J. A., Williams, M. V., Scott, T., Parker, R. M., Green, D., Junling, R., Peel, J. (2002). Functional health literacy and the risk of hospital admission among Medicare managed care enrollees. *American Journal of Public Health*, 92 (8), 1278–1283.

Baker, D. W., Wolf, M. S., Feinglass, J., & Thompson, J. A. (2008). Health literacy, cognitive abilities, and mortality among elderly persons. *Journal of General Internal Medicine*, 23 (6), 723–726.

Ball CT, O'Callaghan J. (2001) Judging the accuracy of children's recall: a statement-level analysis. *J Exp Psychol Appl.* 7(4):331-45

Bartlett, E. E., Grayson, M., Barker, R., Levine, D. M., Golden, A., & Libber, S. (1984). The effects of physician communication skills on patient satisfaction, recall and adherence. *Journal of Chronic Diseases*, 37, 755–764.

Belli RF, Weiss PS, Lepkowski JM, (1999). Dynamics of survey interviewing and the quality of survey reports: age comparisons. Schwarz N, Park D, Knauper B, Sudman

S, ed. *Cognition, Aging and Self-Reports* 303 -307. Psychology Press, Philadelphia, PA.

Bennett, C. L., Ferreira, M. R., Davis, T. C., Kaplan, J., Weinberger, M., Kuzel, T., Seday, M., Sartor, O. (1998). Relation between literacy, race, and stage of presentation among low-income patients with prostate cancer. Journal of Clinical Oncology: *Official Journal of the American Society of Clinical Oncology*, 16 (9), 3101–3104.

Berger, P., Luckmann, T. (1966) *The social construction of reality*. Garden City, NY: Doubleday.

Berner, E., Graber, M. (2008), Overconfidence as a Cause of Diagnostic Error in Medicine, *The American Journal of Medicine,* Volume 121, Issue 5, S2 - S23

Berntsen, D. (2001). Involuntary memories of emotional events: Do memories of traumas and extremely happy events differ? *Applied Cognitive Psychology*, 15, S135–S158.

Bird, Steven J; (2004). Hands-on versus demonstration teaching methods: the effect on memory in older adults. *The University of Toledo Digital Repository*.

Bourke, J. (2014) *The Story of Pain: From Prayer to Painkillers*. Oxford: Oxford University Press.

Bradshaw, P. W., Ley, P., Kincey, J. A. and Bradshaw, J. (1975), Recall of Medical Advice: Comprehensibility and Specificity. *British Journal of Social and Clinical Psychology*, 14: 55-62.

Brick C., McCully SN., Updegraff JA., Ehret PJ., Areguin MA., Sherman DK. (2016) Impact of Cultural Exposure and Message Framing on Oral Health Behaviour: Exploring the Role of Message Memory. *Med Decis Making*. 36(7):834-43.

Brown, P., Zavestoski, S., McCormick, S., Mayer, B., Morello-Frosch, R. and Gasior, R. (2004) Embodied health movements: uncharted territory in social movement research, *Sociology of Health & Illness*, 26, 1, 1–31.

Brown S., Park D., (2002) Roles of age and familiarity in learning health information, *Educational Gerontology*, 28:8, 695-710.

Bruner, J. (1991) The narrative construction of reality. *Critical Inquiry* 18.

Burton C.M., King L.A. (2004) The health benefits of writing about intensely positive experiences. *J. Res. Personal*. 38:150–63.

Bury, M. (1982) Chronic illness as a biographical disruption, *Sociology of Health & Illness*, 4, 2, 167–82.

Cameron, C. (1996). Patient compliance: Recognition of factors involved and suggestions for promoting compliance with therapeutic regimens. *Journal of Advanced Nursing*, 24, 244–250.

Carley, K. (1993). Coding choices for textual analysis: A comparison of content analysis and map analysis. *Sociological Methodology*, 23, 75–126.

Cavalli, A. (1985) II tempo dei giovani. Bologna: II Mulino.

Chafe W. (1990). Some things that narratives tell us about the mind. *In Narrative Thought and Narrative Language*, ed. BK Britton, AD Pelligrini. Hillsdale, NJ: Erlbaum.

Christianson, S.-A. (1992). Emotional stress and eyewitness memory: A critical review. *Psychological Bulletin*, 112, 284–309.

Coates, V. E., & Boore, J. R. P. (1996). Knowledge and diabetes self-management. *Patient Education and Counseling*, 29, 99–108.

Cohen, Gillian, and Rosalind Java. 1995. “Memory for Medical History: Accuracy of Recall.” *Applied Cognitive Psychology* 9 (4): 273–88.

Corbin, J.M. and Strauss, A. (1990), Grounded theory research: procedures, canons, and evaluative criteria, *Qualitative Sociology*, Vol. 13 No. 1, pp. 3-21.

Corbin, J., & Strauss, A. (2008). *Basics of qualitative research*. (3rd ed.). Thousand Oaks, CA: Sage Publications, Inc.

Crews WD, Jefferson AL, Bolduc T, Elliott JB, Ferro NM, Broshek DK, Barth JT, Robbins MK. (2001). Neuropsychological dysfunction in patients suffering from end-stage chronic obstructive pulmonary disease. *Arch Clin Neuropsychol.* 16(7):643-52.

Crook, T., Ferris, S. and McCarthy, M. (1979), The Misplaced-Objects Task: A Brief Test for Memory Dysfunction in the Aged. *Journal of the American Geriatrics Society*, 27: 284-287.

Cunningham, D., Nugent, C. and Slodden, C. (2010) The durability of collective memory: reconciling the ‘Greensboro Massacre’, *Social Forces*, 88, 4, 1517–42.

Cutler RL, Fernandez- Llimos F, Frommer M, Benrimoj, C., Garcia-Cardenas, V. (2018) Economic impact of medication non-adherence by disease groups: a systematic review. *BMJ Open*;8: e016982.

Dalgleish, T., Hauer, B., & Kuyken, W. (2008). The mental regulation of autobiographical recollection in the aftermath of trauma. *Current Directions in Psychological Science*, 17, 259–263.

Danziger, K. (2008). *Marking the Mind. Cambridge*: Cambridge University Press.

De Connick, F., Godard, F. (1990) L’approche biographique à l’épreuve de l’interprétation, *Revue Français de sociologie* 31.

Della Sala S., *Forgetting* (2010). Psychology Press; 1 edition.

DeWalt, D. A., Berkman, N. D., Sheridan, S., Lohr, K. N., & Pignone, M. P. (2004). Literacy and health outcomes: a systematic review of the literature. *Journal of General Internal Medicine,* 19 (12), 1228–1239.

Dinges, D. F., Whitehouse, W. G., Orne, E. C., Powell, J. W., Orne, M. T., & Erdelyi, M. H. (1992). Evaluating hypnotic memory enhancement (hypermnesia and reminiscence) using multi-trial forced recall. *Journal of Experimental Psychology: Learning, Memory, and Cognition*, 18(5), 1139-1147.

Drysdale EE, Grubb NR, Fox KA, O’Carroll RE. Chronicity of memory impairment in long-term out-of-hospital cardiac arrest survivors. *Resuscitation 2000*; 47:27–32.

Ebbinghaus, H. (1885/1964). *Memory: A contribution to experimental psychology*. Oxford: Dover.

Elzinga, B. M., Bakker, A., Bremner, J. D. (2005). “Stress-induced cortisol elevations are associated with impaired delayed, but not immediate recall,” *Psychiatry Research*, vol. 134, no. 3, pp. 211–223, 2005.

Erskine, A., Morley, S. and Pearce, S. (1990). Memory for pain: a review. *Pain*, 41, 255-379.

Ferguson, C.J., Cruz, A.M. & Rueda, S.M. (2008). Gender, video game playing habits and visual memory tasks. *Sex Roles* 58: 279.

Fink, A. (2005). *Conducting Research Literature Reviews: From the Internet to Paper* (2nd ed.). Thousand Oaks, California: Sage Publications.

Finney S., Corbett M. (2007) ERP implementation: a compilation and analysis of critical success factors, *Business Process Management Journal*, Vol. 13 Issue: 3, pp.329-347.

FrankelRM,Quill TE, McDaniel SH. (2003). *The Biopsychosocial Approach: Past, Present, Future*. Rochester, NY: Univ. Rochester Press

Frattaroli, J. (2006). Experimental disclosure and its moderators: A meta-analysis. *Psychological Bulletin*, 132(6).

Glaser, B. G. (1992). *Emergence vs forcing: Basics of grounded theory analysis*. Mill Valley, CA: Sociology.

Glaser, B. G., & Holton, J. (2004). Remodelling grounded theory. Forum Qualitative Sozialforschung/Forum: *Qualitative Social Research*, 5(2), Art. 4.

Grober, E., Hall, C. B., Hahn, S. R., & Lipton, R. B. (2011). Memory Impairment and Executive Dysfunction are Associated with Inadequately Controlled Diabetes in Older Adults. *Journal of Primary Care & Community Health*, 2(4), 229–233.

Grubb Neil R, O'Carrol Ronan, Cobbe Stuart M, Sirel Jane, Fox Keith A A. (1996). Chronic memory impairment after cardiac arrest outside hospital. *British Medical Journal*, 313 :143.

Grubb NR, Fox KA, Smith K, Best J, Blane A, Ebmeier KP, Glabus MF, O'Carroll RE. (2000). Memory impairment in out-of-hospital cardiac arrest survivors is associated with global reduction in brain volume, not focal hippocampal injury. *Stroke*. 31:1509–1514.

Halbwachs, M. (1925/1994) *Les cadres sociaux de la mémoire*. Paris: Albin Michel.

Halbwachs, M. (1950/1997) *La mémoire collective*. Paris: Albin Michel.

Hampton, J. R., Harrison, M. J., Mitchell, J. R., Prichard, J. S., & Seymour, C. (1975). Relative contributions of history-taking, physical examination, and laboratory investigation to diagnosis and management of medical outpatients. *British Medical Journal*, 2(5969), 486–489.

Hanon O., Vidal JS., de Groote P., Galinier M., Isnard R., Logeart D., Komajda M. (2014) Prevalence of memory disorders in ambulatory patients aged ≥70 years with chronic heart failure (from the EFICARE study). *Am J Cardiol*. 1;113(7):1205-10.

Hardie, N. A., Kyanko, K., Busch, S., Losasso, A. T., & Levin, R. A. (2011). Health literacy and health care spending and utilization in a consumer-driven health plan. *Journal of Health Communication*, 16 (Suppl 3), 308–321.

Holman, Jeff and Zaidi, Farhan, (2010). *The Economics of Prospective Memory*. Available at SSRN: https://ssrn.com/abstract=1662183. [Last accessed 05/09/2018]

Homedes, Nuria, Ugalde, Antonio (1994). Research on patient compliance in developing countries. *Bulletin of PAHO*, 28(l).

Hoppe MJ, Morrison DM, Gillmore MR, Beadnell B, Higa DH, Leigh BC. (2008). Agreement of daily diary and retrospective measures of condom use. *AIDS and behaviour*. 12(1):113-117.

Hufford M.R; Shiffman S. (2003). Assessment Methods for Patient-Reported Outcomes. *Disease Management & Health Outcomes*, Volume 11, Issue 2.

Hunter, M., Philips, C. and Rachman, S., (1979) Memory for pain. *Pain*, 6, 35-46.

Huttenlocher, Janellen, Hedges, Larry V., Bradburn, Norman M. (1990). *Journal of Experimental Psychology: Learning, Memory, and Cognition,* Vol 16(2), 196-213.

Iphofen, R. (1999) Coping with a perforated life: a case study in managing the stigma of petit mal epilepsy, *Sociology*, 24, 3, 447–63.

Jansen J, van Weert J, van der Meulen N, van Dulmen S, Heeren T, Bensing J. (2008) Recall in older cancer patients: measuring memory for medical information. *Gerontologist,* 48(2):149-57.

Jedlowski, P., (2001), 'Memory and sociology: themes and issues', *Time and Society*, 10 (1): 29–44.

Jessen F, Wiese B, Cvetanovska G, Fuchs A, Kaduszkiewicz H, Kölsch H, Luck T, Mösch E, Pentzek M, Riedel-Heller SG, Werle J, Weyerer S, Zimmermann T, Maier W, Bickel H. (2007). Patterns of subjective memory impairment in the elderly: association with memory performance. *Psychol Med*. 2007 Dec;37(12):1753-62.

Jones G, Tabassum V, Zarow GJ, Ala TA. (2015). The inability of older adults to recall their drugs and medical conditions. *Drugs Aging*. 32(4):329-36.

Kalichman, S. C., & Rompa, D. (2000). Functional health literacy is associated with health status and health-related knowledge in people living with HIV-AIDS. *Journal of Acquired Immune Deficiency Syndromes*, 25 (4), 337–344.

Kassirer JP. (1983) Teaching clinical medicine by iterative hypothesis testing. Let's preach what we practice. *N Engl J Med*.309(15):921-923.

Kaufman G1, Birks Y. (2009) Strategies to improve patients' adherence to medication. Nurs Stand. 23(49):51-7.

Keeble, W; Cobbe, S M. (2002). Patient recall of medication details in the outpatient clinic. Audit and assessment of the value of printed instructions requesting patients to bring medications to clinic. *Postgraduate medical journal*, Volume 78, Issue 922.

Keightley, E., (2010), 'Remembering research: memory and methodology in the social sciences', *International Journal of Social Research Methodology*, 13 (1): 55–70.

Kenny, D.T. (2004) Constructions of chronic pain in doctor–patient relationships: bridging the communication chasm, *Patient education and counseling*, 52, 3, 297–305.

Kessels R., Patients' memory for medical information. (2003). *J R Soc Med* 96:219–222.

Kintsch, W. (1998). *Comprehension: A paradigm for cognition*. New York: Cambridge University Press.

Koutstaal, W., & Schacter, D. L. (1997). Intentional forgetting and voluntary thought suppression: Two potential methods for coping with childhood trauma. In L. J. Dickstein, M. B. Riba, & J. M. Oldham (Eds.), *Review of Psychiatry:* Vol. 16 (pp. II-79–II-121). Washington, DC: American Psychiatric Press.

Kugelmann, R. (1999) Complaining about chronic pain, *Social Science and Medicine*, 49, 12, 1663–76.

Kutner, M., Greenberg, E., Ying, J., & Paulson, C. (2006). *The health literacy of America's adults' results from the 2003 National Assessment of Adult Literacy* (NCES 2006–483). Washington DC: US Department of Education, National Centre for Education Statistics.

Labban JD, Etnier JL. (2011) Effects of acute exercise on long-term memory. *Res Q Exerc Sport.* 82(4):712-21.

Labov W. (1982). Speech actions and reaction in personal narrative. In *Analyzing Discourse: Text and Talk*, ed.

Larson, Dale G., and Robert L. Chastain. (1990). "Self-concealment: Conceptualization, Measurement, and Health Implications." *Journal of Social and Clinical Psychology* 9(4):439-55.

Lazare A., Putnam S.M., Lipkin M. (1995) Three Functions of the Medical Interview. In: Lipkin M., Putnam S.M., Lazare A., Carroll J.G., Frankel R.M. (eds) *The Medical Interview. Frontiers of Primary Care.* Springer, New York, NY.

Ley, P., Bradshaw, P., Eaves, D., & Walker, C. (1973). A method for increasing patients' recall of information presented by doctors. *Psychological Medicine*, 3(2), 217-220.

Ley, P. (1988). *Communicating with patients: Improving communication, satisfaction, and compliance.* New York: Croom Helm.

Lincoln, Alisa K., Wallis Adams and Mara Eyllon. (2017) The Double Stigma of Limited Literacy and Mental Illness: Examining Barriers to Recovery and Participation among Public Mental Health Service Users. *Society and Mental Health*. Vol. 7(3) 121–141.

Linde C. (1993). *Life Stories: The Creation of Coherence*. New York: Oxford Univ. Press.

Link, Bruce G., and Jo C. Phelan. (2006). "Stigma and Its Public Health Implications." *The Lancet* 367:528-29.

Linton, S.J. and Gotestam, K.G. (1983) A clinical comparison of two pain scales: correlation, remembering chronic pain, and a measure of compliance. *Pain*. 17, 57-65.

Lipson-Smith R., Hyatt A., Murray A., Butow P., Hack TF., Jefford M., Ozolins U., Hale S., Schofield P. (2018) Measuring recall of medical information in non-English-speaking people with cancer: *A methodology. Health Expect.* 21(1):288-299.

Loewenstein, George, Ted O 'Donoghue, and Matthew Rabin (2003) Projection Bias in Predicting Future Utility, *Quarterly Journal of Economics*, 118, 1209 -1248.

Lutfey, Karen, and Jeremy Freese. (2005). "Toward Some Fundamentals of Fundamental Causality: Socioeconomic Status and Health in the Routine Clinic Visit for Diabetes." *American Journal of Sociology* 110(5):1326-72.

Maehara Y., (2017). 'Psychological and Neural Functions of Working Memory in Social Contexts', in Tsukiura T., and Umeda S., Memory in a Social Context Brain, *Mind, and Society*. Springer, pp.39-57.

Macioti, M. (1985) *Biografia, storia e società*. Napoli: Liguori.

Martin L., Dimatteo M., (2014) *The Oxford Handbook of Health Communication, Behaviour Change, and Treatment Adherence*. Oxford University Press.

Matheis RJ1, Schultheis MT, Tiersky LA, DeLuca J, Millis SR, Rizzo A. (2007) Is learning and memory different in a virtual environment? *Clin Neuropsychol*. 2007 Jan;21(1):146-61.

Means, B., Loftus, E.F. (1991) When personal history repeats itself: decomposing memories for recurring events. *Applied cognitive psychology*. 5, 297-318.

Meeusen AJ., Porter R. (2015) Patient-Reported Use of Personalized Video Recordings to Improve Neurosurgical Patient-Provider Communication. *Cureus*. 2;7(6): e273.

McAdams, D. P. (2004). The Redemptive Self: Narrative Identity in America Today. In D. R. Beike, J. M. Lampinen, & D. A. Behrend (Eds.), *Studies in self and identity. The self and memory*. New York, NY, US: Psychology Press.

McGuire, L. C. (1996). Remembering what the doctor said: Organization and older adults' memory for medical information. *Experimental Aging Research*, 22, 403–428.

McKinlay, J. (1975). Who is Really Ignorant--Physician or Patient? *Journal of Health and Social Behaviour*, 16(1), 3-11.

McKinstry B1, Watson P, Elton RA, Pinnock H, Kidd G, Meyer B, Logie R, Sheikh A. (2011). Comparison of the accuracy of patients' recall of the content of telephone and face-to-face consultations: an exploratory study. *Postgrad Med J*. 87(1028):394-9.

McLean, K. C., & Breen, A. V. (2009). Processes and content of narrative identity development in adolescence: Gender and well-being. *Developmental Psychology*, 45(3), 702–710.

Misra S1, Daly B, Dunne S, Millar B, Packer M, Asimakopoulou K. (2013) Dentist-patient communication: what do patients and dentists remember following a consultation? Implications for patient compliance. *Patient Prefer Adherence*. 17;7:543-9.

Monajemi, Alireza; Rikers, Remy M.J.P. (2011) The role of patient management in medical expertise development: Extending the contemporary theory. *International Journal of Person Centered Medicine*, [S.l.], v. 1, n. 1, p. 161-166.

Morrow, D. G., Leirer, V. O., & Altieri, P. A. (1992). Aging, expertise, and narrative processing. *Psychology and Aging*, 7(3), 376-388.

Namer, G. (1987a) *Mémoire et societé.* Paris: Klincksieck.

Nielsen-Bohlman, L. N., Panzer, A. M., & Kindig, D. A. (2004). *Health literacy: A prescription to end confusion.* Washington, DC: National Academies Press.

Norwell, K.T., Gaston-Johansson, F. and Fridh, G. (1987) Remembrance of labor pain: how valid are retrospective pain measurements? **Pain**, 31, 77-86.

Nørby, S. (2015). Why forget? On the adaptive value of memory loss. *Perspectives on Psychological Science*, 10(5), 551–578.

Nouchi, R., Ryuta Kawashima, R. (2017) Benefits of "Smart Ageing" Interventions Using Cognitive Training, Brain Training Games, Exercise, and Nutrition Intake for Aged Memory Functions in Healthy Elderly People. in Tsukiura T., and Umeda S., *Memory in a Social Context Brain, Mind, and Society*. Springer, pp.301-312.

Nutbeam, D. (2000). Health literacy as a public health goal: A challenge for contemporary health education and communication strategies into the 21st century. *Health Promotion International*, 15(3), 259–267.

Oakley, A. (2016) A small sociology of maternal memory. *The Sociological Review*, Vol. 64, 533–549.

Paasche-Orlow, M. K., Parker, R. M., Gazmararian, J. A., Nielsen-Bohlman, L. T., & Rudd, R. R. (2005). The prevalence of limited health literacy. *Journal of General Internal Medicine*, 20, 175–184.

Parikh, N. S., Parker, R. M., Nurss, J. R., Baker, D. W., & Williams, M. V. (1996). Shame and health literacy: the unspoken connection. *Patient Education & Counseling*, 27 (1), 33–39.

Parsons T. 1951. *The Social System*. New York: Free Press

Pennebaker, J. W., and Chung, C. (2007). “Expressive writing, emotional upheavals, and health,” in *Foundations of Health Psychology*, eds H. S. Friedman and R. C. Silver (New York, NY: Oxford University Press), 263–284.

Personal Injury Team Ireland (2017). *Medical Negligence in hospitals in Ireland*. http://www.personalinjuryireland.ie/medical-negligence-in-hospitals-in-ireland.

Porter, S., & Peace, K. A. (2007). The scars of memory: A prospective, longitudinal investigation of the consistency of traumatic and positive emotional memories in adulthood. *Psychological Science*, 18, 435–441.

Posma ER, van Weert JC, Jansen J, Bensing JM. (2009). Older cancer patients' information and support needs surrounding treatment: An evaluation through the eyes of patients, relatives and professionals. *BMC Nurs.* 19;8:1.

Pressler SJ, Therrien B, Riley PL, Chou CC, Ronis DL, Koelling TM, Smith DG, Sullivan BJ, Frankini AM, Giordani B. (2011). Nurse-Enhanced Memory Intervention in Heart Failure: the MEMOIR study. *J Card Fail.* (10):832-43.

Radvansky G, (2017) *Human Memory*. 3rd Edition. Taylor & Francis.

Rand, C. S. (2000). “I took the medicine like you told me, doctor”: Self-report of adherence with medical regimens. In A. A. Stone, J. S. Turkkan, C. A. Bachrach, J. B. Jobe, H. S. Kurtzman, & V. S. Cain (Eds.), *The science of self-report: Implications for research and practice* (pp. 257-276). Mahwah, NJ, US: Lawrence Erlbaum Associates Publishers.

Ray, D., Gomillion, S., Pintea, A., Hamlin, I. (2019). On Being Forgotten: Memory and Forgetting Serve as Signals of Interpersonal Importance. *Journal of Personality and Social Psychology*. Vol. 116, No. 2, 259–276.

Redelmeier DA, Dickinson VM. (2012) Judging whether a patient is actually improving: more pitfalls from the science of human perception. *J Gen Intern Med*. 27(9):1195-9.

Redman, T. (2016) Assess Whether You Have a Data Quality Problem. *Harvard Business Review.* https://hbr.org/2016/07/assess-whether-you-have-a-data-quality-problem.

Rennick JE, Rashotte J. (2009). Psychological outcomes in children following pediatric intensive care unit hospitalization: a systematic review of the research. *J Child Health Care*. 13(2):128-49.

Roche, P. and Gigsber, K. (1986) A comparison of memory for induced ischaemic pain and chronic rheumatoid pain. *Pain*, 25, 337-343.

Rousseau, D. M., Manning, J., & Denyer, D. (2008). *Evidence in Management and Organizational Science: Assembling the Field's Full Weight of Scientific Knowledge Through Syntheses.* SSRN eLibrary. Retrieved from http://papers.ssrn.com/sol3/papers.cfm?abstract_id=1309606

Rubin, G., George, A., Chinn, D., & Richardson, C. (2003). Errors in general practice: development of an error classification and pilot study of a method for detecting errors. *Quality & Safety in Health Care*, 12(6), 443–447.

Rubin D., Umanath S., (2015) Event Memory: A Theory of Memory for Laboratory, Autobiographical, and Fictional Events. *Psychol Rev*. 122(1): 1–23.

Sandler G. (1980). The importance of the history in the medical clinic and the cost of unnecessary tests. *Am Heart J*. 100(6 Pt 1):928-31.

Santos, P., Sá, L., Couto, L., Hespanhol, A. (2017) Health literacy as a key for effective preventive medicine, *Cogent Social Sciences* 3:1407522.

Sarkar U., Schillinger D., Bibbins-Domingo K., Nápoles A., Karliner L., Pérez-Stable E., (2011) Patient–physicians' information exchange in outpatient cardiac care: Time for a heart to heart? *Patient Education and Counseling*, Volume 85, Issue 2, Pages 173-179.

Schacter, D. L (1999) The seven sins of memory: Insights from psychology and cognitive neuroscience. *American Psychologist*, [s. l.], v. 54, n. 3, p. 182–203.

Schank, R. C. (1980), Language and Memory. *Cognitive Science*, 4: 243-284.

Schoth, D. E., Radhakrishnan, K., & Liossi, C. (2020). A systematic review with subset meta-analysis of studies exploring memory recall biases for pain-related information in adults with chronic pain. *Pain reports*, 5(2), e816.

Scott C. Brown & Denise C. Park (2002) Roles of age and familiarity in learning health information, *Educational Gerontology*, 28:8, 695-710.

Schillinger, D., Grumbach, K., Piette, J., Wang, F., Osmond, D., Daher, C., Palacios, J., Diaz Sullivan, G., Bindman, A. (2002). Association of health literacy with diabetes outcomes. *The Journal of the American Medical Association*, 288 (4), 475–482.

Schillinger, D., Piette, J., Grumbach, K., Wang, F., Wilson, C., Dahler, C., Bindman, A. B. (2003). Closing the loop: Physician communication with diabetic patients who have low health literacy. *Archives of Internal Medicine*, 163, 83–90.

Schwabe, L., & Wolf, O. T. (2010). Learning under stress impairs memory formation. *Neurobiology of Learning and Memory*, 93, 183–188.

Schwabe, L., Wolf, O. T., & Oitzl, M. S. (2010). Memory formation under stress: Quantity and quality. *Neuroscience and Biobehavioral Reviews*, 34, 584–591.

Scott, T. L., Gazmararian, J. A., Williams, M. V., & Baker, D. W. (2002). Health literacy and preventive health care use among Medicare enrolees in a managed care organization. *Medical Care*, 40 (5), 395–404.

Seligman, H. K., Wang, F. F., Palacios, J. L., Wilson, C. C., Daher, C., Piette, J. D., & Schillinger, D. (2005). Physician notification of their diabetes patients' limited health literacy. A randomized, controlled trial. *Journal of General Internal Medicine*, 20 (11), 1001–1007.

Shimizu H. (2017) Experimental Psychology Approaches to Human Memory. In: Tsukiura T., Umeda S. (eds) *Memory in a Social Context*. Springer, Tokyo.

Shostak, S., Fox, N. (2012) Forgetting and remembering epilepsy: collective memory and the experience of illness. *Sociology of Health & Illness* Vol. 34 No. 3. pp. 362–378.

Smith-DiJulio K, Mitchell ES, Woods NF.(2005). Concordance of retrospective and prospective reporting of menstrual irregularity by women in the menopausal transition. *Climacteric*. 2005 Dec;8(4):390-7.

Smith, Wendy B; Safer, Martin A. (1993). Effects of present pain level on recall of chronic pain and medication use. *Pain* Volume 55, Issue 3, Pages 355-361.

Strauss, A. and Corbin, J. (1990a), *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*, Sage, Newbury Park, CA.

Stirratt M., Dunbar-Jacob J., Crane H., Simoni J., Czajkowski S., Hilliard M., Aikens J., Hunter C., Velligan D., Huntley K., Ogedegbe G., Rand C., Schron E., Nilsen W. (2015) Self-report measures of medication adherence behaviour: recommendations on optimal use. *Transl Behav Med.* 5(4): 470–482.

Sudore, R. L., Yaffe, K., Satterfield, S., Harris, T. B., Mehta, K. M., Simonsick, E. M.,Newman, A., Rosano, C., Rooks R., Rubin, S., Ayonayon, H., Schillinger, Dean. (2006). Limited literacy and mortality in the elderly: The health, aging, and body composition study. *Journal of General Internal Medicine*, 21 (8), 806–812.

Tarr, J., Cornish, F., Gonzalez-Polledo, E. (2018) Beyond the binaries: reshaping pain communication through arts workshops, *Sociology of Health & Illness* Vol. 40 No. 3, pp. 577–592.

Tomasello, M. (1999). *The cultural origins of human cognition*. Cambridge, MA: Harvard University Press.

Toye, F., Seers, K., Allcock, N., Briggs, M., et al. (2013) Patients' experiences of chronic non-malignant musculoskeletal pain: a qualitative systematic review, *British Journal of General Practice*, 63, 617, e829–41.

Tulving E., Pearlstone Z., (1966) Availability versus accessibility of information in memory for words. *Journal of Verbal Learning and Verbal Behavior* Volume 5, Issue 4, Pages 381-391.

Tulving, E. (1974). Cue-dependent forgetting. *American Scientist*, 62, 74–82.

Turner, J., & Kelly, B. (2000). Emotional dimensions of chronic disease. *Western Journal of Medicine*, 172(2), 124–128.

Twomey, M., Sammon, D., Nagle, T. and O'Raghallaigh, P. (2018) 'A check list designed to improve memory recall amongst CF patients', *ECIS 2018: Twenty-Sixth European Conference on Information Systems*, Portsmouth, UK, 23-26 June.

Twomey M., Sammon D., Nagle T. (2020) The Tango of Problem Formulation: A Patient's/Researcher's Reflection on an Action Design Research Journey. *J Med Internet Res* 2020;22(7)

United States Medicine (2013). *It's far more important to know what person the disease has than what disease the person has*. http://www.usmedicine.com/editor-in-chief/its-far-more-important-to-know-what-person-the-disease-has-than-what-disease-the-person-has/ [Last accessed 31/10/2018].

Vance DE, Farr KF. (2007) Spaced Retrieval for enhancing memory: implications for nursing practice and research. *J Gerontol Nurs*. 2007 Sep;33(9):46-52.

Waldron CA1, van der Weijden T, Ludt S, Gallacher J, Elwyn G. (2011) What are effective strategies to communicate cardiovascular risk information to patients? A systematic review. *Patient Educ Couns.* 82(2):169-81.

Webster, Jeffrey D. (2001). "The Future of the Past: Continuing Challenges for Reminiscence Research." Pp. 159-85 in *Narrative Gerontology: Theory, Research, and Practice* edited by G. Kenyon, B. de Vries, and P. Clark. New York: Springer.

Weiss, B. D., & Coyne, C. (1997). Communicating with patients who cannot read. *The New England Journal of Medicine*, 337 (4), 272–274.

Werner, A. and Malterud, K. (2003) It is hard work behaving as a credible patient: encounters between women with chronic pain and their doctors, *Social Science and Medicine*, 57, 8, 1409–19.

World Health Organization. (2009) *Health Promotion Track 2: Health literacy and health behaviour*. http://www.who.int/healthpromotion/conferences/7gchp/track2/en/ [last Accessed 21/01/2019].

World Health Organization. (2016) *Diagnostic Errors: Technical Series on Safer Primary Care.* Available from: https://apps.who.int/iris/bitstream/handle/10665/252410/9789241511636-eng.pdf;jsessionid=205337C2D53A8298D47551310C5FA00C [last Accessed 07/07/2020].

Young, A. W., Hay, D. C., & Ellis, A. W. (1985). The faces that launched a thousand slips: Everyday difficulties and errors in recognizing people. *British Journal of Psychology*, 76, 495–523.

Zhou Q., (2015) Coffee consumption and risk of endometrial cancer: a dose-response meta-analysis of prospective cohort studies. *Scientific Reports*, volume 5, Article number: 13410.

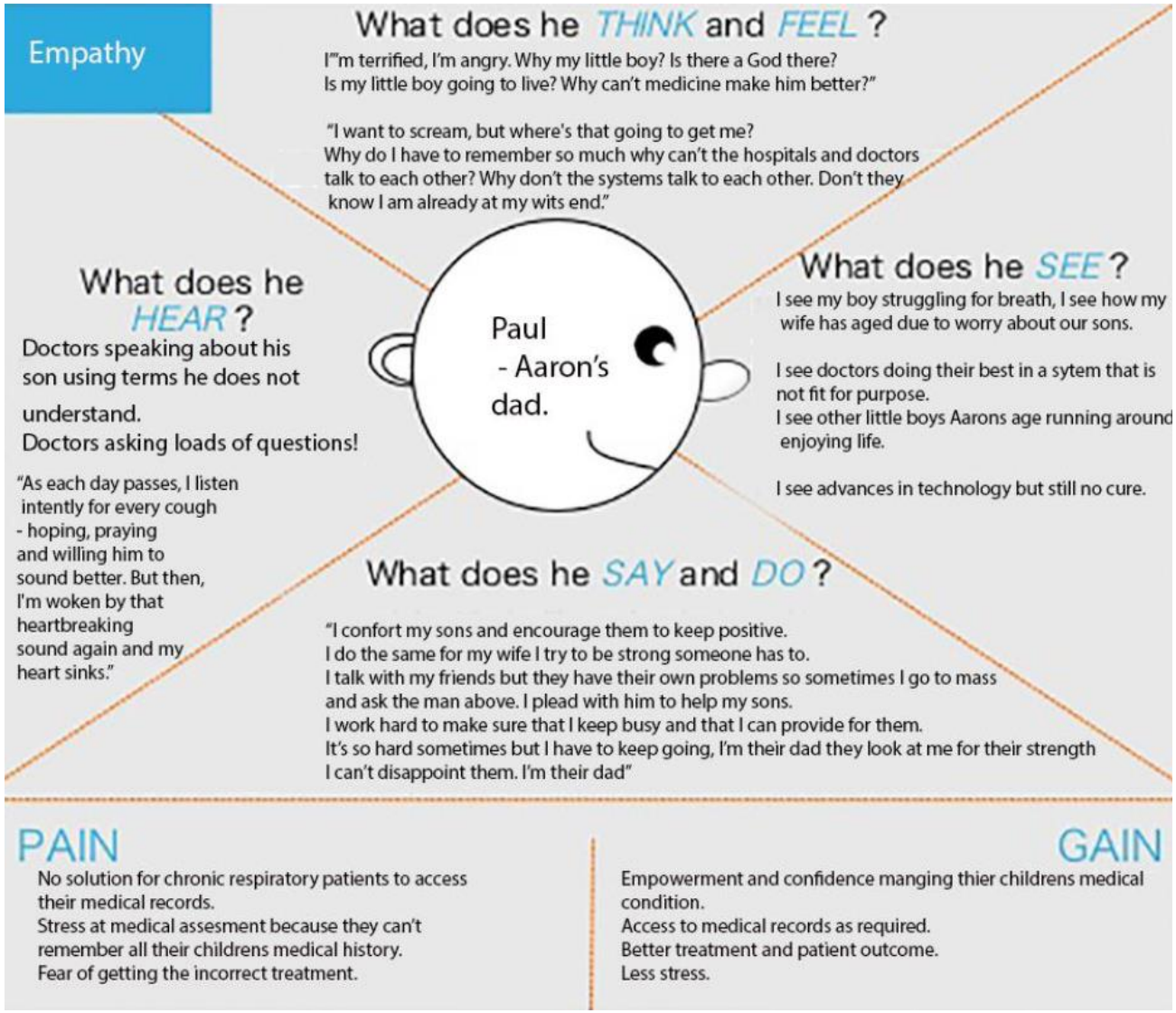
Appendix D - Check List Evaluations Summary

Check List Evaluation Summary				
Intervention & Evaluation	**Metric**	**Version 1** **Date:** Oct 2016 - Nov 2016	**Version 2** **Date:** Jan 2017 - Feb 2017	**Version 3** **Date:** Mar 2017
	Completeness	61% completeness achieved in terms of key information that needed to be recorded for recall purposes. Identified gaps in the Check List Completeness i.e. urine tests, bone density, sugar levels etc.	High scores of over 80% in completeness were achieved, albeit with further work to be done in the area of medication and emotional state metrics.	Met evaluation goals for Completeness (100%) in terms of key information that needed to be recorded for *recall* purposes for CF patients and carers.
	Usability	100% were comfortable using the sheet, but we identified a major usability issue regarding the uniformity of colour which was hindering the use of the Check List in the pressurised environment of the appointment. Participants reported having difficulty finding their way back to particular sections (quickly) if they were distracted in an appointment. 100% of participants claimed they were however comfortable using the Check List in their appointment.	High scores of over 80% in usability but space requirements were raised as an issue. As expected, the use of colour to separate the sections really added to the usability of the Check List where it was now found to be more logical, simpler to use and easier to find one's way back to a particular section if distracted. 17/18 participants give a 4 or 5 out of 5 in terms of ease of use.	Met evaluation goals for Usability 95% in the pressurised environment of the medical appointment facilitating *information recall*.
	Robustness	Recognition by 78% of participants that a change in behaviour would be required and also a commitment by 94% to change behaviour in the future if the issue of *information recall* was to be addressed using the Check List	High degree of robustness (albeit with some engagement techniques required for 3/18 of the Group). Recognition now by 83% of participants that they would need to change their behaviour in the future if the issue of *information recall* was to be solved using the Check List.	15/18 of participants were using the Check List in all appointments for *information recall* with the remaining 3 requiring the use of engagement techniques to keep involved.
	Impacts	100% of the participants felt that the Check List had aided them in some way in their respective medical appointments, especially in their ability to *remember data.*	Early signs of increases in Empowerment and Engagement by participants.	In Version 3 we sought to really understand the Impacts that the sheet was making in appointments and on the CF patient/carers who had now been using the Check List (albeit in different forms) for almost six months. Impacts are really seen particularly in the **reduction of Stress** and the **increase in Empowerment** that the patient /carer felt as a result of using the artefact and being able to *recall their medical information*.

Appendix E - Version One of Check List

Appointment Check List	
Date:	Doctor:
Reason for apt. (Please Circle one -fill in before apt)	
Routine Apt. / Last Problem / Annual Assessment / Other	
Current Symptoms (fill in before apt)	Date of onset: (fill in before apt)
1	
2	
3	
Current Medication & doses: (fill in before apt)	
1	9
2	10
3	11
4	12
5	Changes to medication: (fill in during apt. if required)
6	
7	
8	
Physio Therapy (fill in before apt)	Physio Therapy Changes (if any)
Airway Clearance Technique used:	1
Frequency:	2
Exercise /Activity:	3
Key Metrics (fill in during apt)	Bowels (fill in before apt)
Weight:	Abdominal pain:
Height:	Bowel Motions:
BMI:	Odour:
FEV1:	Colour:
FVC:	Other Notes (fill in as required)
O2 sat:	
Blood Pressure:	
Color of Sputum	
Last Sputum Culture	
Questions / comments for doctor (fill in before apt)	
1	
2	
3	
Comments by doctor (fill in during apt)	
1	
2	
3	

Appendix F - Empathy Map



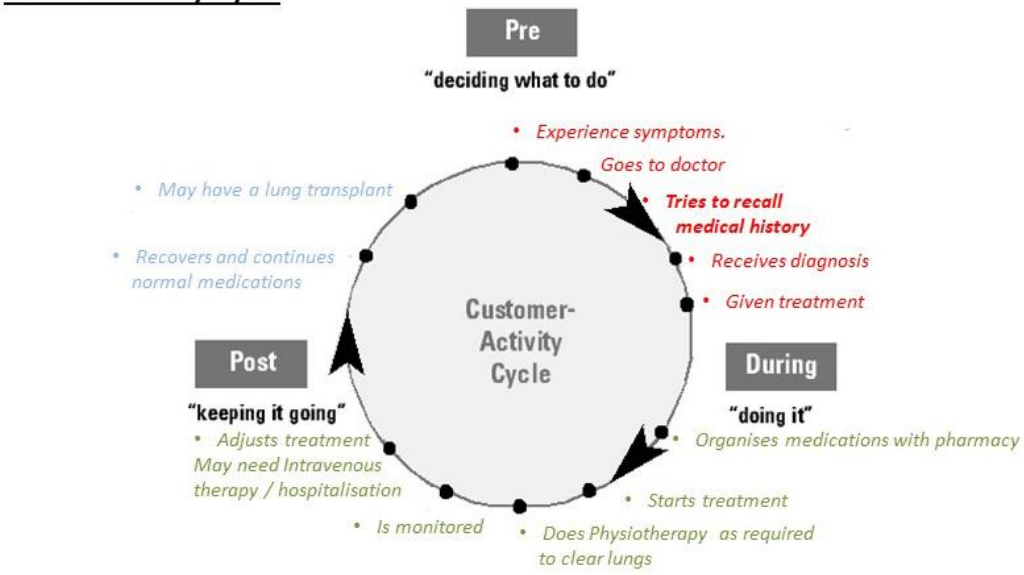
Appendix G - Personas

Tommy is 4 and has Cystic Fibrosis. His parents are Joe and Carol. His sister is Kim and he has a brother David. He lost his sister Emma to CF two years ago. He is a playful child but hates hospital. He gets scared with all the prodding and poking and the big scary machines and the funny noises. He just want to play with his brother and sister at home.

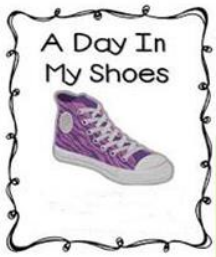
Joe and Carol have a son Tommy who has Cystic Fibrosis and has been in hospital 5 times in the last year. Their have two kids David and Kim. They lost their daughter Emma two years ago. to CF. Joe and Carol are terrified when they hear Tommy cough. They find the pressure of a sick child plus other life commitments extremely difficult.

Appendix H - Journey Maps: Activity Cycle

Patient Activity Cycle



Appendix I - Journey Map



The *Good* days, The *Ok* days and the *Bad* days

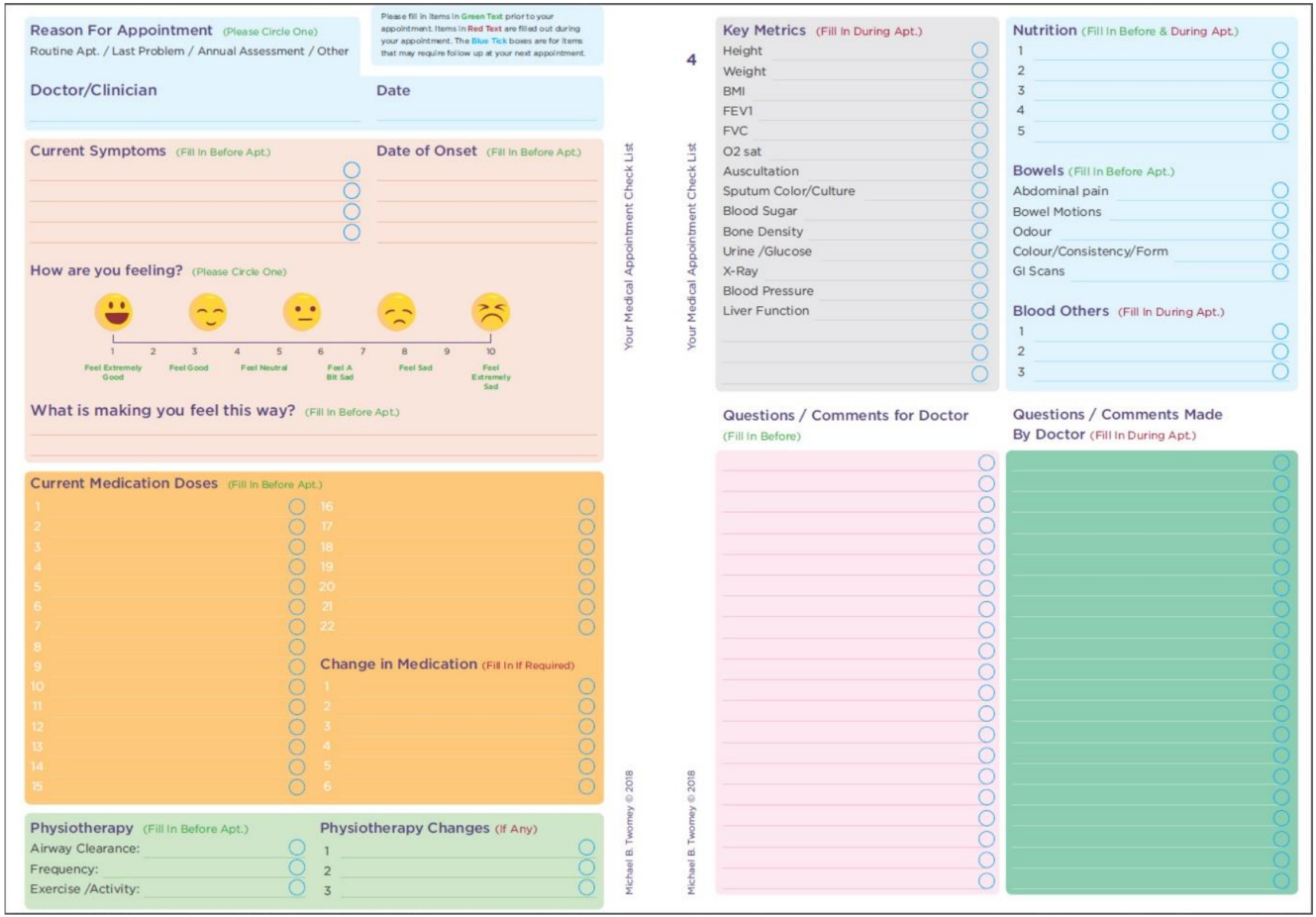
Good	• Everything seems Normal, • Can Exercise • Take medications 40 tablets/day • Take Nebuliser/Podhaler • Very Happy
Ok	• Lung Feel tight, I wheeze, and I am Breathless • Increased medication – 2 sometimes 3 antibiotics • Headaches sometimes • Low appetite • Go to the doctor have Lung Function tests etc • Stressed
Bad	• On intravenous antibiotics, • Very breathless, sometimes chest pain (pleurisy) , No energy, • No appetite, headaches, very stress • Green sputum • Feeling down, sometimes scared

A Day in the Life of a Teenage CF Patient

Appendix J - Declarative Long-Term Memory Types

Term	Description	References
Episodic Memory	Episodic memories refer to particular episodes or occasions in our lives. They are linked to the time and place of the event in which the information was attained via sensory inputs. Episodic memories are more catalogued and forgotten very quickly. Episodic memory requires knowledge of the self.	Ranvansky, 2017
Semantic Memory	Semantic memories are generalised and encyclopaedic in nature, and are not tied to a specific time or location. As a stable knowledge that you share with society, once established these memories are forgotten extremely slowly and are highly interrelated. Semantic memory requires conscious awareness.	Ranvansky, 2017
Spatial Memory	Spatial memory is that aspect of the memory responsible for the logging of information regarding the world/location a person lives in and involves spatial positioning. Having portrayals within working memory, STM and LTM, our spatial memory is vital for navigating to a location as it is akin to a cognitive map.	Ranvansky, 2017
Autobiographical Memory	Autobiographical memory builds on episodic accounts, that is to say episodic memories (a series of individual events in the past) taken together make up a person's autobiographical memory or personal history that links a person to their past, present, and future self. In essence it is our unique life story.	Habermas & Bluck, 2000; McAdams, 2001
Prospective Memory	Prospective memory involves an intent to carry out a future act being formed/encoded in memory. Later on, an encounter with an environmental stimulus acts like a memory trigger/prompt to perform that action.	Einstein & McDaniel, 1990; Harris, 1984; Harris & Wilkins, 1982; Meacham & Leiman 1975)

Appendix K - Booklet Version of Check List



Reason For Appointment (Please Circle One)
Routine Apt. / Last Problem / Annual Assessment / Other

Please fill in items in Green Text prior to your appointment. Items in Red Text are filled out during your appointment. The Blue Tick boxes are for items that may require follow up at your next appointment.

Doctor/Clinician

Date

Current Symptoms (Fill In Before Apt.)

Date of Onset (Fill In Before Apt.)

How are you feeling? (Please Circle One)

1 Feel Extremely Good · 2 · 3 Feel Good · 4 · 5 Feel Neutral · 6 · 7 Feel A Bit Sad · 8 Feel Sad · 9 · 10 Feel Extremely Sad

What is making you feel this way? (Fill In Before Apt.)

Current Medication Doses (Fill In Before Apt.)

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22

Change in Medication (Fill In If Required)
1 2 3 4 5 6

Physiotherapy (Fill In Before Apt.)
Airway Clearance:
Frequency:
Exercise /Activity:

Physiotherapy Changes (If Any)
1 2 3

Your Medical Appointment Check List

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4

Your Medical Appointment Check List

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Key Metrics (Fill In During Apt.)
Height
Weight
BMI
FEV1
FVC
O2 sat
Auscultation
Sputum Color/Culture
Blood Sugar
Bone Density
Urine /Glucose
X-Ray
Blood Pressure
Liver Function

Nutrition (Fill In Before & During Apt.)
1 2 3 4 5

Bowels (Fill In Before Apt.)
Abdominal pain
Bowel Motions
Odour
Colour/Consistency/Form
GI Scans

Blood Others (Fill In During Apt.)
1 2 3

Questions / Comments for Doctor (Fill In Before)

Questions / Comments Made By Doctor (Fill In During Apt.)

Appendix L - Version Two of Check List

Appointment Check List V2	
Date:	Doctor/ Clinician:
Reason for apt. (Please Circle one - fill in before apt)	
Routine Apt. / Last Problem / Annual Assessment / Other	
Current Symptoms (fill in before apt)	Date of onset: (fill in before apt)
1	
2	
3	
Current Medication & doses: (fill in before apt)	
1	9
2	10
3	11
4	12
5	Changes to medication: (fill in during apt. if required)
6	
7	
8	
Physiotherapy (fill in before apt)	
Airway Clearance:	Physio Therapy Changes (if any)
Frequency:	
Exercise /Activity:	
Key Metrics (fill in during apt)	Nutrition (fill in before & during apt)
Height:	
Weight:	
Liver Function:	
BMI:	
FEV1:	
FVC:	Bowels (fill in before apt)
O2 sat:	Abdominal pain:
Auscultation:	Bowel Motions:
Sputum Color/Culture:	Odour:
Blood Sugar:	Colour/Consistency/Form:
Bone Density:	GI Scans:
Urine /Glucose:	Bloods Other (fill in during apt)
Liver Function:	
X-Ray	
Questions / comments for doctor (fill in before apt)	
1	
2	
3	
Comments by doctor (fill in during apt)	
1	
2	
3	

Appendix M - Databases Searched

Database	
AACR Journals	Ingenta Connect
Academic Search Complete	InTech
ACM Digital Library	IOPscience
AIS eLibrary	JAMA Network
BMJ Journals	Journals@Ovid
Cambridge Core	JStor
CINAHL Plus MDPI	MEDLINE
Cochrane Library	OECD iLibrary
DOAJ	OmniFile (Wilson)
Dove Press	Oxford Academic Journals
EBSCO Online	Project MUSE
EDP Open	ProQuest Central
Embase	PsycArticles
IEEE Xplore Digital Library	Psychology and Behavioural Science Collection
Psycinfo	PubMed
Sage Journals	ScienceDirect
Scopus	Social Sciences
SocIndex	Springerlink
Taylor & Francis Online	Wiley Online Library
Wires	

Appendix N - 49 Papers Analysed

Paper Number	Author	Title	Source	Year
P1	McKinlay, John B;	Who is really ignorant--physician or patient?	Journal of Health and Social Behavior	**1975**
P2	Crook, Thomas; Ferris, Steven; McCarthy, Martin	The Misplaced-Objects Task: A Brief Test for Memory Dysfunction in the Aged	Journal of the American Geriatrics Society, Volume 27, Issue 6	**1979**
P3	Schank, Roger C;	Language and Memory	Cognitive science	**1980**
P4	by Baddeley, Alan; Wilson, Barbara	Comprehension and working memory: A single case neuropsychological study	Journal of Memory and Language, Volume 27, Issue 5	**1988**
P5	Huttenlocher, Janellen; Hedges, Larry V; Bradburn, Norman M;	Reports of elapsed time: Bounding and rounding processes in estimation.	Journal of Experimental Psychology: Learning, Memory, and Cognition	**1990**
P6	Dinges, David F; Whitehouse, Wayne G; Orne, Emily Carota; Powell, John W; Orne, Martin T; Erdelyi, Matthew H;	Evaluating hypnotic memory enhancement (hypermnesia and reminiscence) using multitrial forced recall.	Journal of Experimental Psychology: Learning, Memory, and Cognition	**1992**
P7	Smith, Wendy B; Safer, Martin A;	Effects of present pain level on recall of chronic pain and medication use	Pain	**1993**
P8	Homedes, Nuria; Ugalde, Antonio;	Research on patient compliance in developing countries	Bulletin of PAHO	**1994**
P9	Grubb, Neil R; O'Carrol, Ronan; Cobbe, Stuart M; Sirel, Jane; Fox, Keith A A	Chronic memory impairment after cardiac arrest outside hospital	BMJ, Volume 313, Issue 7050	**1996**

Paper Number	Author	Title	Source	Year
P10	Albert, Steven M; Weber, Christine M; Todak, George; Polanco, Carmen; Clouse, Ronda; McElhiney, Martin; Rabkin, Judith; Stern, Yaakov; Marder, Karen	An Observed Performance Test of Medication Management Ability in HIV: Relation to Neuropsychological Status and Medication Adherence Outcomes	AIDS and Behavior, Volume 3, Issue 2	**1999**
P11	Belli, Robert F; Weiss, Paul S; Lepkowski, James M;	Dynamics of survey interviewing and the quality of survey reports: Age comparisons	Cognition, aging, and self-reports	**1999**
P12	Drysdale, Emma E; Grubb, Neil R; Fox, Keith A.A; O'Carroll, Ronan E	Chronicity of memory impairment in long-term out-of-hospital cardiac arrest survivors	Resuscitation, Volume 47, Issue 1	**2000**
P13	Neil R Grubb; Keith A A Fox; Karen Smith; Jonathan Best	Memory impairment in out-of-hospiral cardiac arrest survivors is associated with global reduction in brain volume, not focal hippocampal injury	Stroke, Volume 31, Issue 7	**2000**
P14	Rand, Cynthia S;	I took the medicine like you told me, doctor: self-report of adherence with medical regimens	The science of self-report: Implications for research and practice	**2000**
P15	Crews, W.David; Jefferson, Angela L; Bolduc, Tara; Elliott, Jennifer B; Ferro, Nikola M; Broshek, Donna K; Barth, Jeffrey T; Robbins, Mark K	Neuropsychological dysfunction in patients suffering from end-stage chronic obstructive pulmonary disease	Archives of Clinical Neuropsychology, Volume 16, Issue 7	**2001**
P16	Ball, Christopher T; O'Callaghan, Janelle;	Judging the accuracy of children's recall: A statement-level analysis.	Journal of Experimental Psychology: Applied	**2001**

Paper Number	Author	Title	Source	Year
P17	Brown, Scott C; Park, Denise C	ROLES OF AGE AND FAMILIARITY IN LEARNING HEALTH INFORMATION	Educational Gerontology, Volume 28, Issue 8	**2002**
P18	Keeble, W; Cobbe, S M	Patient recall of medication details in the outpatient clinic. Audit and assessment of the value of printed instructions requesting patients to bring medications to clinic	Postgraduate medical journal, Volume 78, Issue 922	**2002**
P19	Albert, Steven M; Flater, Susanne R; Clouse, Ronda; Todak, George; Stern, Yaakov; Marder, Karen	Medication Management Skill in HIV: I. Evidence for Adaptation of Medication Management Strategies in People with Cognitive Impairment. II. Evidence for a Pervasive Lay Model of Medication Efficacy	AIDS and Behavior, Volume 7, Issue 3	**2003**
P20	Hufford M.R; Shiffman S	Assessment Methods for Patient-Reported Outcomes	Disease Management & Health Outcomes, Volume 11, Issue 2	**2003**
P21	Rubin, Greg; George, Ajay; Chinn, DJ; Richardson, Clive;	Errors in general practice: development of an error classification and pilot study of a method for detecting errors	BMJ Quality & Safety	**2003**
P22	Bird, Steven J;	Hands-on versus demonstration teaching methods: the effect on memory in older adults	The University of Toledo Digital Repository	**2004**

Paper Number	Author	Title	Source	Year
P23	Elzinga, Bernet M; Bakker, Abraham; Bremner, J. Douglas	Stress-induced cortisol elevations are associated with impaired delayed, but not immediate recall	Psychiatry Research, Volume 134, Issue 3	**2005**
P24	Smith-DiJulio, Kathleen; Mitchell, E Sullivan; Woods, N Fugate;	Concordance of retrospective and prospective reporting of menstrual irregularity by women in the menopausal transition	Climacteric	**2005**
P25	Vance, David E; Farr, Kenneth F	Spaced Retrieval for enhancing memory: implications for nursing practice and research	Journal of gerontological nursing, Volume 33, Issue 9	**2007**
P26	JESSEN, FRANK; WIESE, BIRGITT; CVETANOVSKA, GABRIELA; FUCHS, ANGELA; KADUSZKIEWICZ, HANNA; KÖLSCH, HEIKE; LUCK, TOBIAS; MÖSCH, EDELGARD; PENTZEK, MICHAEL; RIEDEL-HELLER, STEFFI G; WERLE, JOCHEN; WEYERER, SIEGFRIED; ZIMMERMANN, THOMAS; MAIER, WOLFGANG; BICKEL, HORST	Patterns of subjective memory impairment in the elderly: association with memory performance	Psychological Medicine, Volume 37, Issue 12	**2007**
P27	Matheis, Robert J; Schultheis, Maria T; Tiersky, Lana A; DeLuca, John; Millis, Scott R; Rizzo, Albert;	Is learning and memory different in a virtual environment?	The Clinical Neuropsychologist	**2007**

Paper Number	Author	Title	Source	Year
P28	Jansen, J; van Weert, J; van der Meulen, N; van Dulmen, S; Heeren, T; Bensing, J	Recall in older cancer patients: Measuring memory for medical information	The Gerontologist, Volume 48, Issue 2	**2008**
P29	Hoppe, Marilyn J; Morrison, Diane M; Gillmore, Mary Rogers; Beadnell, Blair; Higa, Darrel H; Leigh, Barbara C;	Agreement of daily diary and retrospective measures of condom use	AIDS and Behavior	**2008**
P30	Ferguson, Christopher J; Cruz, Amanda M; Rueda, Stephanie M;	Gender, video game playing habits and visual memory tasks	Sex Roles	**2008**
P31	Rennick, Janet E; Rashotte, Judy	Psychological outcomes in children following pediatric intensive care unit hospitalization: a systematic review of the research	Journal of Child Health Care, 06/2009, Volume 13, Issue 2	**2009**
P32	Posma, E.R; van Weert, J.C.M; Jansen, J; Bensing, J.M	Older cancer patients' information and support needs surrounding treatment: An evaluation through the eyes of patients, relatives and professionals	BMC Nursing, Volume 8, Issue 1	**2009**
P33	Kaufman, Gerri; Birks, Yvonne;	Strategies to improve patients' adherence to medication	Nursing Standard (through 2013)	**2009**
P34	Holman, Jeff; Zaidi, Farhan;	The economics of prospective memory	www.ssrn.com	**2010**

Paper Number	Author	Title	Source	Year
P35	Pressler, Susan J; Therrien, Barbara; Riley, Penny L; Chou, Cheng-Chen; Ronis, David L; Koelling, Todd M; Smith, Dean G; Sullivan, Barbara Jean; Frankini, Ann-Marie; Giordani, Bruno	Nurse-Enhanced Memory Intervention in Heart Failure: The MEMOIR Study	Journal of Cardiac Failure, Volume 17, Issue 10	**2011**
P36	McKinstry, Brian; Watson, Philip; Elton, Robert A; Pinnock, Hilary; Kidd, Gillian; Meyer, Barbara; Logie, Robert; Sheikh, Aziz	Comparison of the accuracy of patients' recall of the content of telephone and face-to-face consultations: an exploratory study	Postgraduate Medical Journal, Volume 87, Issue 1028	**2011**
P37	Grober, Ellen; Hall, Charles B; Hahn, Steven R; Lipton, Richard B	Memory Impairment and Executive Dysfunction are Associated with Inadequately Controlled Diabetes in Older Adults	Journal of Primary Care & Community Health, Volume 2, Issue 4	**2011**
P38	Waldron, Cherry-Ann; van der Weijden, Trudy; Ludt, Sabine; Gallacher, John; Elwyn, Glyn;	What are effective strategies to communicate cardiovascular risk information to patients? A systematic review	Patient education and counseling	**2011**
P39	Monajemi, Alireza; Rikers, Remy MJP;	The role of patient management in medical expertise development: Extending the contemporary theory	International Journal of Person Centered Medicine	**2011**
P40	Labban, Jeffrey D; Etnier, Jennifer L;	Effects of acute exercise on long-term memory	Research quarterly for exercise and sport	**2011**
P41	Redelmeier, Donald A; Dickinson, Victoria M	Judging Whether a Patient is Actually Improving: More Pitfalls from the Science of Human Perception	Journal of General Internal Medicine, Volume 27, Issue 9	**2012**

Paper Number	Author	Title	Source	Year
P42	Misra, Sara; Daly, Blánaid; Dunne, Stephen; Millar, Brian; Packer, Mark; Asimakopoulou, Koula	Dentist-patient communication: what do patients and dentists remember following a consultation? Implications for patient compliance	Patient preference and adherence, 2013, Volume 7	**2013**
P43	Amin, Hafeezullah; Malik, Aamir S;	Human memory retention and recall processes	Neurosciences	**2013**
P44	Hanon, Olivier; Vidal, Jean-Sébastien; de Groote, Pascal; Galinier, Michel; Isnard, Richard; Logeart, Damien; Komajda, Michel	Prevalence of memory disorders in ambulatory patients aged ≥70 years with chronic heart failure (from the EFICARE study)	The American journal of cardiology, Volume 113, Issue 7	**2014**
P45	Jones, GaToya; Tabassum, Vajeeha; Zarow, Gregory J; Ala, Thomas A	The Inability of Older Adults to Recall Their Drugs and Medical Conditions	Drugs & Aging, Volume 32, Issue 4	**2015**
P46	Meeusen, Andrew J; Porter, Randall;	Patient-reported use of personalized video recordings to improve neurosurgical patient-provider communication	Cureus	**2015**
P47	Brick, Cameron; McCully, Scout N; Updegraff, John A; Ehret, Phillip J; Areguin, Maira A; Sherman, David K	Impact of Cultural Exposure and Message Framing on Oral Health Behavior: Exploring the Role of Message Memory	Medical Decision Making, Volume 36, Issue 7	**2016**
P48	Ahn, Christine S; Culp, Leonora; Huang, William W; Davis, Scott A; Feldman, Steven R;	Adherence in dermatology	Journal of Dermatological Treatment	**2017**

Paper Number	Author	Title	Source	Year
P49	Lipson-Smith, Ruby; Hyatt, Amelia; Murray, Alexandra; Butow, Phyllis; Hack, Thomas F; Jefford, Michael; Ozolins, Uldis; Hale, Sandra; Schofield, Penelope	Measuring recall of medical information in non-English-speaking people with cancer: A methodology	Health Expectations, Volume 21, Issue 1	**2018**

Appendix O - Categorisation Example

Categorisation according to Systems of the Human Body

Systems of the human body																																		
Skeleton	Integumentary	Renal	Digestive		Reproductive			Immune	Endocrine			Circulatory			Nervous																Respiratory				
Arthritis	Dermatology	Renal	Dental	Gastrointestinal	Maternity	Gynaecological	Sexual Health	AIDS/HIV	Dysthyroidism	Acromegaly	Diabetes	Stroke	Cardiac	Anemia	Chronic Pain	NeuroPsychological	Brain Injuries	PTSD	Alcoholism	Amnesia	Schizophrenic	Parkinsons	Neuroscience	Alzheimers	Psychological	Cognition	Epilepsy	Dementia	COPD	Cystic Fibrosis	Not specified	Asthma	Dyspnea

Appendix P - Tools Used to Aid Memory Recall

Decade		1975-1985	1986-1996	1997-2007	2008-2018	Totals	
Memory Intervention						Focus	Touched Upon
Informational	**Emphasis**			(Brown et al., 2002);	(Jansen et al., 2008); (Posma et al., 2009); (McKinstry et al., 2011);	**0**	**4**
	Educational		(Homendes et al., 1994)	(Rand et al., 2000); (Brown et al., 2002);	(Jansen et al., 2008); (Posma et al., 2009); (Kaufmann et al., 2009); (Pressler et al., 2011); (McKinstry et al., 2011); (Misra et al., 2013); (Hanon et al., 2014); (Meeusen et al., 2015); (Brick et al., 2016); (Ahn et al., 2017); (Lipson-Smith et al., 2018)	**5**	**9**
	Personalisation				(Jansen et al., 2008); (Posma et al., 2009); (McKinstry et al., 2011);	**1**	**2**
	Message Framing				(Waldron et al., 2011); (Brick et al., 2016)	**1**	**1**
	Spaced Retrieval			(Vance et al., 2007)		**1**	**0**
	Contextualisation				(Misra et al., 2013)	**0**	**1**

Decade			1975-1985	1986-1996	1997-2007	2008-2018	Totals	
Memory Intervention							Focus	Touched Upon
Traditional	Paper	Lists			(Keeble et al., 2002)	(Jones et al., 2015); (Lipson-Smith et al., 2018)	0	3
		Brown Bag			(Keeble et al., 2002)	(Jones et al., 2015)	1	1
		Paper & Pencil				(Meeusen et al., 2015); (Lipson-Smith et al., 2018); (Hufford et al., 2003)	0	3
		Check lists				(Lipson-Smith et al., 2018)	0	1
		Q Prompt Sheets				(Posma et al., 2009)	0	1
Temporal		Paper Diary		(Grubb et al., 1996)	(Albert et al., 2003); (Hufford et al., 2003)		2	1
		Weekly Pill Organizers			(Rand et al., 2000); (Albert et al., 2003); (Vance et al., 2007)	(Hanon et al., 2014)	1	3
		Calendar			(Smith-DiJulio et al., 2005); (Vance et al., 2007)		1	1
		Daily Dairies			(Hufford et al., 2003)	(Hoppe et al., 2008); (Ahn et al., 2017)	2	1
		Electronic Diary		(Smith et al., 1993)	(Rand et al., 2000); (Hufford et al., 2003)		2	1

Decade			1975-1985	1986-1996	1997-2007	2008-2018	Totals	
Memory Intervention							Focus	Touched Upon
Technology		Electronic Pagers			(Albert et al., 2003)		0	1
		Computer			(Hufford et al., 2003)		0	1
		Interactive Voice Response System			(Hufford et al., 2003)		0	1
		Audio /Recordings		(Homendes et al., 1994)	(Bird et al., 2004)	(McKinstry et al., 2011); (Redelmeier et al., 2012); (Misra et al., 2013); (Meeusen et al., 2015); (Lipson-Smith et al., 2018)	2	5
		Video Recordings			(Ball et al., 2001)	(Meeusen et al., 2015); (Lipson-Smith et al., 2018)	2	1
		Alarms/ Reminders			(Rand et al., 2000)	(Holman et al., 2010)	1	1
		Gaming				(Ferguson et al., 2008)	1	0
		Virtual Reality			(Matheis et al., 2007)		1	0
		Apps				(Ahn et al., 2017)	1	0
		Texts				(Ahn et al., 2017)	1	0
		Patient Portals				(Ahn et al., 2017)	1	0

Decade		1975-1985	1986-1996	1997-2007	2008-2018	Totals	
Memory Intervention						Focus	Touched Upon
Cognitive	Hypermnesia		(Dinges et al., 1992)			1	0
	Hypnosis		(Dinges et al., 1992)			1	0
	Neuroplasticity				(Pressler et al., 2011)	1	0
Human to/with Human	Training		(Grubb et al., 1996)		(Posma et al., 2009); (Pressler et al., 2011); (Lipson-Smith et al., 2018)	2	2
	Family/Friends				(Jansen et al., 2008); (Posma et al., 2009); (Grober et al., 2011); (Hanon et al., 2014); (Lipson-Smith et al., 2018)	1	4
	Show Me, Show Me				(Posma et al., 2009); (McKinstry et al., 2011);	0	2
	Interviewer Tailoring			(Belli et al., 1999)		1	0
	Other Strategies	(Crook et al., 1979)	(Dinges et al., 1992)	(Rand et al., 2000); (Crews et al., 2001); (Bird et al., 2004)	(Posma et al., 2009); (McKinstry et al., 2011); (Redelmeier et al., 2012); (Hanon et al., 2014)	0	9
Physical	Exercise				(Labban et al., 2011)	1	0

Appendix Q Representative Data

Figure 1-3 Data The patient/carer experience *now*

Effort of Patient/Carer Recall:

Concept	Before the medical Appointment	*During* the Appointment		*After* Appointment
	Preparation	**Elicitation Phase**	**Elucidation Phase**	**After**
Effort to Recall	**Primary Data:** **Type: Interview - DS3** **Q.** When asked: Rate your memory recall effort ***before*** the medical appointment between 1-5 (where 1 - recall effort is low, to 5 - recall effort is high)? **A.** 78 % of participants gave a 1/5 in a Likert scale, indicating a low recall effort. **Primary Data:** **Type: Interview - DS3** **Carer 4**: *"No more diary, now I use the check list and record everything, with final preparation the day before. Its structure is perfect".* **Appointment Experience:** Has attended approx. 38 medical appointments. **Patient 3:** "*As a result of coming so prepared, with everything so well laid out in the check list, …. it was easier to remember stuff".* **Appointment Experience:** Has attended approx. 180 medical appointments.	**Primary Data:** **Type: Interview – DS 3** **Q.** When asked: Rate your memory recall effort *during* the **medical history/ *Elicitation* phase** of medical appointment between 1-5 (where 1 - recall effort is low, to 5 - recall effort is high)? **A.** 81% of participants gave a 2/5 in a Likert scale, indicating a moderate recall effort. **Primary Data:** **Type: Interview - DS3** **Patient 6**: *"It's so difficult to recall everything on the spot, but with the check list I can do just that."* **Appointment Experience:** Has attended approx. 132 medical appointments. **Patient 1:** *"The doctor asks so many questions, including medications, symptoms, illnesses, other medical appointments, wellbeing etc. and with the check list I'm ready for them, no more forgetting".* **Appointment Experience:** Has attended approx. 272 medical appointments.	**Primary Data:** **Type: Interview - DS3** **Q.** When asked: Rate your memory effort *during* the ***explanatory/ elucidation* phase** of medical appointment between 1-5 (where 1 - memory effort is low, to 5 - memory effort is high)? **A.** 89% of participants gave a 1/5 in a Likert scale, indicating a low memory effort. **Primary Data:** **Type: Interview - DS3** **Patient 2:** *"It's incredible how much information the doctor gives me during the medical appointment. Using the check list, I no longer have to remember it all. I no longer feel so overwhelmed"* **Appointment Experience:** Has attended approx. 96 medical appointments.	**Primary Data:** **Type: Interview - DS3** **Q.** When asked: Rate your memory recall effort ***after*** the medical appointment between 1-5 (where 1 - recall effort is low, to 5 - recall effort is high)? **A.** 72 % of participants gave a 2/5 in a Likert scale, indicating a low recall effort. **Primary Data:** **Type: Interview - DS3** **Carer 11:** *"When I go home, I'm now able to recall everything back to my husband, and remember every step of Tommy's treatment schedule exactly, I don't have to worry about forgetting something"* **Appointment Experience:** Has attended approx. 44 medical appointments.

Figure 1-3 Data The patient/carer experience *now*

Effort to Recall - Theoretical Context:

Concept	*Before* the medical Appointment	*During* the Appointment		*After* Appointment
	Preparation	**Elicitation Phase**	**Elucidation Phase**	**After**
Effort to Recall	**Literature DS6:** Rehearsal for an appointment aids memory recall (White et al., 1995). Tactics that aid memory recall /information retrieval such as cues, hints, or indeed testing patients recall, have all been found to aid memory recall /information retrieval (Tulving & Pearlstone, 1966; Koutstaal & Schacter, 1997).	**Literature DS6:** The use of check lists in health care is now widespread as they have proven to be so beneficial in preventing memory failures (Stock et al., 2015). In complex environments, not only do check lists help, they are required for successful memory recall (Gawande, 2010).	**Literature DS6:** Reports show that memory recall /information retrieval of this phase of the medical appointment directly impact patient adherence and other self-managing activities, such as regime change (McPherson et al., 2008). Structuring of data aids human understanding and augments memory recall (Ackermann et al., 2016; Mandler, 1967).	

Figure 1-3 Data The patient/carer experience *now*

Patient/Carer Stress:

Concept	***Before*** **the medical Appointment**	***During*** **the Appointment**		***After*** **Appointment**
	Preparation	**Elicitation Phase**	**Elucidation Phase**	**After**
Stress	**Primary Data:** **Type: Interview - DS3** **Q.** When asked: Rate your stress levels ***before*** the medical appointment between 1-5 (where 1 - your stress is low, to 5 - your stress is high)? **A.** 78 % of participants gave a 2/5 in a Likert scale indicating a low to moderate stress. **Primary Data:** **Type: Interview - DS3** **Carer 4:** *"I used to be stressed the night before my little girls' medical appointment, however the check list has really helped me with that, as it helps me focus and gives the confidence that I am prepared as I know that I have all the before sections complete. Fabulous."* **Appointment Experience:** Has attended approx. 38 medical appointments.	**Primary Data:** **Type: Interview - DS3** **Q.** When asked: Rate your stress levels ***during*** **the *medical history /elicitation* phase** of the medical appointment between 1-5 (where 1 - your stress is low, to 5 - your stress is high)? **A.** 72 % of participants gave a 3/5 in a Likert scale indicating a low to moderate stress. **Primary Data:** **Type: Interview - DS3** **Patient 6:** *"It's so difficult to recall everything on the spot, but with the check list I can do just that. It takes away the stress and makes me fell so in control, so empowered".* **Appointment Experience:** Has attended approx. 132 medical appointments.	**Primary Data:** **Type: Interview - DS3** **Q.** When asked: Rate your stress levels ***during*** **the *explanatory /elucidation* phase** of medical appointment between 1-5 (where 1 - your stress is low, to 5 - your stress is high)? **A.** 78 % of participants gave a 2/5 in a Likert scale indicating a low to moderate stress. **Primary Data:** **Type: Interview - DS3** **Carer 1:** *"With the check list for the first time I could really hear what the doctor was saying to me".* **Appointment Experience:** Has attended approx. 64 medical appointments. **Patient 6:** *The Check List won't take all the stress away, but it sure does help a lot. More than I thought it would to be honest. It's amazing what a bit of paper can do".* **Appointment Experience:** Has attended approx. 132 medical appointments.	**Primary Data:** **Type: Interview - DS3** **Q.** When asked: Rate your stress levels ***after*** the medical appointment between 1-5 (where 1 - your stress is low, to 5 - your stress is high)? **A.** 89 % of participants gave between a 2/5 and 3/5 in a Likert scale indicating a moderate stress. **Primary Data:** **Type: Interview - DS3** **Carer 2:** *"When I go home, I'm now able to recall everything back to my husband, and remember every step of Tommy's treatment schedule exactly, I don't have to worry about forgetting something".* **Appointment Experience:** Has attended over 57 medical appointments.

Figure 1-3 Data The patient/carer experience *now*

Patient/Carer Stress - Theoretical Context:

Concept	***Before*** **the medical Appointment**	***During*** **the Appointment**		***After*** **Appointment**
	Preparation	**Elicitation Phase**	**Elucidation Phase**	**After**
Stress	**Literature DS6:** The degree of preparation by the patient for a medical appointment has impacts on its outcomes (Martin et al., 2014).	**Literature DS6:** Complexity results in stress, therefore a check list should be easy to read, understand and to fill out. (Weiser et al., 2010)	**Literature DS6:** Reducing stress *during* the *explanatory phase* of the medical appointment helps patients encode and retain more information (Kessels, 2003).	**Literature DS6:** Improvements in patient/carer memory recall (especially *after* the medical appointment) result in better patient adherence, health outcomes and patient satisfaction (Schraa et al., 1982).

Figure 1-3 Data The patient/carer experience *now*

Patients/Carers Sense of Empowerment:

Concept	*Before* the medical Appointment	*During* the Appointment		*After* Appointment
	Preparation	**Elicitation Phase**	**Elucidation Phase**	**After**
Empowerment	**Primary Data:** **Type: Interview - DS3** **Q.** When asked: Rate your sense of empowerment from 1-5 (where 1 - I don't feel empowered, to 5 - I feel very empowered) *during* each of the following stages of the medical appointment: 1) *Before* 2) *Medical history* phase 3) *Explanatory* phase 4) *After*? **A.** 83% of participants gave a 4/5 or 5/5 in a Likert scale. This was consistent through each phase. **Primary Data:** **Type: Interview - DS3** **Patient 2**: *"I feel at long last that I have a real voice in the what happens with my body. Before I felt voiceless, unheard, not comfortable speaking about my concerns. Now I have the courage to speak my mind. I can't believe how good it feels."* **Appointment Experience:** Has attended approx. 96 medical appointments. **Patient 4**: *"The doctor assumes that the treatment he recommends is ok with me, he never really asks me. But now when I come with the check list, he knows I mean business, that I am serious about my health, that I want to be heard, I want to have my say. I think it has really helped our relationship."* **Appointment Experience:** Has attended over 250 medical appointments. **Carer 7:** *"No more diary, now I use the check list and record everything, with final preparation the day before. Its structure is perfect, it helps me with everything, no more fuss".* **Appointment Experience:** Has attended over 44 medical appointments. **Carer 2:** *"It's so difficult to recall everything on the spot, but with the check list I can do just that. It takes away the stress and makes me fell so in control, so empowered".* **Appointment Experience:** Has attended over 57 medical appointments.			

Figure 1-3 Data The patient/carer experience *now*

Patients/Carers Sense of Empowerment - Theoretical Context:

Concept	*Before* the medical Appointment	*During* the Appointment		*After* Appointment
	Preparation	**Elicitation Phase**	**Elucidation Phase**	**After**
Empowerment	**Literature DS6:** *"The process of empowerment is in part about enabling use of resources.....personal and psychological empowerment is driven by achieving change in power relations"* (Pulvirenti et al., 2011, p.308). Patient empowerment can be augmented through the use of well-designed solutions (Coulter and Ellins, 2007). (Chronic patients/carers are known to engage in their illness more when they feel empowered to do so, additionally, an increased sense of empowerment is known to improve the efficacy of treatments as it augments adherence to therapy regimes (Prigge et al., 2015), possibly even reducing, patient anxiety (Giardina et al., 2014). Mika et al. (2007) contend that the very act of publicising questions empowers patients to ask questions, and also aids them in prioritising the questions of greatest consequence to them.			

Figure 1-3 Data The patient/carer experience *now*

The Process:

Concept	*Before* the medical Appointment	*During* the Appointment		*After* Appointment
	Preparation	**Elicitation Phase**	**Elucidation Phase**	**After**
Process	This phase is prior to the medical appointment, when the patient/carer uses the Check List to prepare for the medical history questions that will be asked. They are also required to prepare for the questions they have for the doctor and to reflect on the emotional state of the patient.	The Check List acts as a memory recall aid in this bi-directional conversation around the patients' medical history, including current wellbeing, present treatments/medication and so on (Cohen et al., 1995). In the region of 46% of the medical appointment consists of this stage, and is vital to the appointments' success (Bickley, 2013).	This phase of the medical appointment is when the doctor imparts and explains the diagnosis, various treatment options, self-care plans, including advice around a variety of disease management topics (Martin et al., 2014). The check list facilitates the capture of all this information for the patient/carer.	The check list aids the phase *after* the medical appointment when the patient/carer replays the medical appointment event to others and to themselves, so they remember and very importantly adhere to agreed treatment regimens (McPherson et al., 2008).

Figure 1-4 Data The patient/carer experience *Before*

Effort of Patient/Carer Recall:

Concept	***Before*** **the medical Appointment**	***During*** **the Appointment**		***After*** **Appointment**
	Preparation	**Elicitation Phase**	**Elucidation Phase**	**After**
Effort of Recall	**Primary Data: - DS2** **Type: Interview** **Q.** When asked: Rate your memory recall effort ***before*** the medical appointment between 1-5 (where 1 - recall effort is low, to 5 - recall effort is high)? **A.** 67% of participants gave a 2/5 or 3/5 in a Likert scale, indicating a moderate recall effort. **Primary Data:** **Type: Interview - DS2** **Carer 1**: *"Sometimes I use a diary to prepare, but sometimes it really difficult to remember everything I need to bring with me. I get so frustrated at times."* **Appointment Experience:** Has attended approx. 64 medical appointments.	**Primary Data:** **Type: Interview - DS2** **Q.** When asked: Rate your memory recall effort *during* the **medical history/ *elicitation* phase** of medical appointment between 1-5 (where 1 - recall effort is low, to 5 - recall effort is high)? **A.** 78% of participants gave a 4/5 or 5/5 in a Likert scale, indicating a high recall effort. **Primary Data:** **Type: Interview - DS2** **Patient 4**: "*It's so difficult to recall everything on the spot, it's like an interrogation at times. I know it's vitally important but it's so challenging at times"* **Appointment Experience:** Has attended approx. 250 medical appointments.	**Primary Data:** **Type: Interview - DS2** **Q.** When asked: Rate your memory effort *during* the ***explanatory/elucidation* phase** of medical appointment between 1-5 (where 1 - memory effort is low, to 5 - memory effort is high)? **A.** 72% of participants gave a 2/5 or 3/5 in a Likert scale, indicating a moderate memory effort. **Primary Data:** **Type: Interview - DS2** **Patient 1:** *"It's incredible how much information comes out of the doctor during the medical appointment. And I'm expected to remember it all. I mean I'm not a machine. I often feel overwhelmed"* ***Appointment* Experience:** Has attended approx. 272 medical appointments.	**Primary Data:** **Type: Interview - DS2** **Q.** When asked: Rate your memory recall effort ***after*** the medical appointment between 1-5 (where 1 - recall effort is low, to 5 - recall effort is high)? **A.** 83% of participants gave a 4/5 or 5/5 in a Likert scale, indicating a high recall effort. **Primary Data:** **Type: Interview - DS2** **Carer 7:** *"When I go home, I'm then expected to be able to recall everything back to my husband, and remember every step of Tommy's treatment schedule exactly, I worry I may forget something".* **Appointment Experience:** Has attended approx. 44 medical appointments.

	Patient 7: *"The night before I try to write down stuff so I am some way prepared for my apt., but remembering everything is really difficult at times.".* **Appointment Experience:** Has attended approx. 124 medical appointments.	**Carer 6:** *"I am very scatty about the medical history of my 3 kids, and find remembering all their histories quite difficult and sometimes I get a bit mixed up"* **Appointment Experience:** Has attended approx. 96 medical appointments. **Type: Survey – DS1** **A.** In a survey of 305 participants 78% reported difficulty in remembering medical history data within the medical appointment.	**Carer 2**: *"I need something to help me remember what happens at every apt. There is just too much for me to remember!"* **Appointment Experience:** Has attended approx. 57 medical appointments. **Type: Survey – DS1** **A.** In a survey of 305 participants 67% also reported difficulty in remembering medical data within the medical appointment. Interestingly, 91.67% also felt that information was been lost within the medical appointment.	**Patient 4:** *"Having moved country 3 times, I find remembering the details of different appointments, in different places, at different times really tough, I get really frustrated at times"* **Appointment Experience:** Has attended approx. 250 medical appointments. **Type: Survey – DS1** **A.** In a survey of 305 participants 67% reported difficulty in remembering data *after* the medical appointment. Interestingly, only 17% recorded any information within the medical appointment.

Figure 1-4 Data The patient/carer experience *Before*

Effort of Patient/Carer Recall - Theoretical Context:

	***Before* the medical Appointment**	***During* the Appointment**		***After* Appointment**
Concept	**Preparation**	**Elicitation Phase**	**Elucidation Phase**	**& After**
Effort of Recall	**Literature DS6:** To improve understanding and memory recall, one needs to be explicit, prioritise and encapsulate the major data points (Jansen, 2008). Lack of rehearsal for an appointment, reduces memory recall (White et al., 1995).	**Literature DS6:** "*Memory for medical history, like other forms of autobiographical memory, is likely to be flawed, incomplete and erroneous"* (Cohen et al., 1995, p.273). The importance of memory recall/information retrieval is indisputable as the accuracy and completeness of data gathering in the history-taking phase of the medical appointment determines diagnostic success (Japp et al., 2018).	**Literature DS6:** Recurring appointments/events are seen to almost merge into one another (Rubin et al., 2015). This phase is directly related to the patients' /carers' adherence and other self-managing actions, such as any alterations to clinical therapies (McPherson et al., 2008), in tandem with, moderated health outcomes and decreased patient/carer satisfaction (Schraa et al., 1982). Research also confirms that as the quantity of material to be remembered grows, the percentage of accurately recalled data deteriorates (McGuire, 1996).	

Figure 1-4 Data The patient/carer experience *Before*

Patient/Carer Stress:

Concept	***Before*** **the medical Appointment**	***During*** **the Appointment**		***After*** **Appointment**
	Preparation	**Elicitation Phase**	**Elucidation Phase**	**After**
Stress	**Primary Data: Type: Interview - DS2** **Q.** When asked: Rate your stress levels ***before*** the medical appointment between 1-5 (where 1 - your stress is low, to 5 - your stress is high)? **A.** 61 % of participants gave a 2/5 in a Likert scale indicating low to moderate stress. **Primary Data: Type: Interview - DS2** **Patient 1:** *"A couple of days before my appointment I can feel my stress levels beginning to rise, I don't know why, it just happens. The day before It can be hard to prepare, to focus when your thinking is so distracting."* **Appointment Experience:** Has attended approx. 272 medical appointments.	**Primary Data: Type: Interview - DS2** **Q.** When asked: Rate your stress levels ***during*** **the *medical history /elicitation* phase** of the medical appointment between 1-5 (where 1 - your stress is low, to 5 - your stress is high)? **A.** 83 % of participants gave a 4/5 or 5/5 in a Likert scale indicating a high stress level. **Primary Data: Type: Interview - DS2** **Patient 5:** *"The doctor asks so many questions, including medications, symptoms, illnesses, other medical appointments, wellbeing etc, it's so stressful".* **Appointment Experience:** Has attended approx. 156 medical appointments. **Patient 6:** *"As a CF patient it's not easy. When I am at the appointment, I feel my heart racing, I am stressed about what the doctor might say about my health."* **Appointment Experience:** Has attended approx. 132 medical appointments. **Type: Survey** – **DS1** In 2015, in a survey of 305 CF participants, 74% reported finding the recalling of medical history stressful.	**Primary Data: Type: Interview - DS2** **Q.** When asked: Rate your stress levels ***during*** **the explanatory /*elucidation* phase** of medical appointment between 1-5 (where 1 - your stress is low, to 5 - your stress is high)? **A.** 72 % of participants gave a 3/5 or 4/5 in a Likert scale indicating a moderate to high stress level. **Primary Data: Type: Interview - DS2** **Carer 2:** *" Sometimes the doctor starts on about what he thinks is going on, and I could be still worrying if I have remembered all my child's medical history correctly*". **Appointment Experience:** Has attended approx. 57 medical appointments. **Patient 3:** *"I would need a brain like a computer to remember all that my doctor is telling me, I feel like screaming stop, slow down, at times".* **Appointment Experience:** Has attended approx. 180 medical appointments.	**Primary Data: Type: Interview - DS2** **Q.** When asked: Rate your stress levels ***after*** the medical appointment between 1-5 (where 1 - your stress is low, to 5 - your stress is high)? **A.** 66% of participants gave between a 2/5 or 3/5 in a Likert scale indicating moderate stress. **Primary Data: Type: Interview - DS2** **Carer 4:** *" I sometimes feel stressed, as the responsibility for my child's health rests firmly on my shoulders. I wouldn't want it any other way, but I suppose making a mistake is something that is always in the back of my mind."* **Appointment Experience:** Has attended over 38 medical appointments.

Figure 1-4 Data The patient/carer experience *Before*

Patient/Carer Stress Levels - Theoretical Context:

Concept	*Before* the medical Appointment	*During* the Appointment		*After* Appointment
	Preparation	**Elicitation Phase**	**Elucidation Phase**	**After**
Stress	**Literature DS6:** In many cases stress levels can increase simply by thinking about or visiting a medical appointment, referred to as *'white coat syndrome'* (Martin et al., 2014).	**Literature DS6:** The medical appointment by its very nature is often a very stressful event for the patient/carer (Turner, 2000). Anxiety levels are reported to hinder information retrieval /memory recall (Kessels, 2003; Jansen, 2008; Safeer, 2005; Ley, 1979).	**Literature DS6:** The ability to give adequate attention for sufficient encoding is often difficult (Kessels, 2003). Individuals with adequate health literacy can face limitations in their health literacy skills during times of illness and stress (Martin et al., 2014).	**Literature DS6:** High anxiety adds to patients' challenges in recalling information, augmenting the chance of nonadherence (Montgomery et al.,1999; Shapiro et al., 1992). Caregivers too find recall *after* an appointment a stressful experience, especially when trying to remember treatment regimens/schedules. (Martin et al., 2014).

Figure 1-4 Data The patient/carer experience *Before*

Patient/Carer Sense of Empowerment:

Concept	(*Before* the medical Appointment)	*During* the Appointment		*After* Appointment
	Preparation	**Elicitation Phase**	**Elucidation Phase**	**After**
Empowerment	**Primary Data:** **Type: Interview - DS2** **Q.** When asked: Rate your sense of empowerment from 1-5 (where 1 - I don't feel empowered, to 5 - I feel very empowered) *during* each of the following stages of the medical appointment: 1) *Before* 2) *Medical history* phase 3) *Explanatory* phase 4) *After*? **A.** 67% of participants gave a 1/5 or 2/5 in a Likert scale. This was consistent through each phase.			
Empowerment	**Primary Data:** **Type: Interview - DS2** **Patient 5**: *" I sometimes feel a bit of a fool when I am asked about my medications, and I can't remember the name of the drug. I mean seriously, some of them I take every day."* **Appointment Experience:** Has attended approx. 156 medical appointments. **Carer 7:** *"When I'm in the appointment it's sometimes like I am in a different country, I find the terms the doctor uses difficult to understand, I wish I had the guts to ask him what they mean".* **Appointment Experience:** Has attended over 44 medical appointments. **Carer 11:** *"I wish I felt more confident whilst inside the appointment, it's tough because I need to be there for my little one. I'm his voice".* **Appointment Experience:** Has attended over 44 medical appointments.			

Figure 1-4 Data The patient/carer experience *Before*

Patient/Carer Sense of Empowerment - Theoretical Context:

Concept	(*Before* the medical Appointment)	*During* the Appointment		*After* Appointment
	Preparation	**Elicitation Phase**	**Elucidation Phase**	**After**
Empowerment	**Literature DS6:** Lack of preparation effects an individual's sense of efficacy/empowerment (Martin et al., 2014). Identified by the World Health Organization as an eminent priority subject matter to be pursued globally (Delnoij et al., 2013). A lack of empowerment can prevent individuals with low health literacy from asking for clarification or additional information (Baker et al., 1996; Parikh et al., 1996). Those who are disempowered in other parts of their lives may not have the confidence to interact with their doctor (Gillespie et al., 2002). It affects an individual's ability to cope with health and illness, in order to increase the individual's well-being (Mead et al., 2008). (Hibbard, et al., 2013) report that those living with greater degrees of patient empowerment were consistent in generating reduced healthcare costs in comparison to those that were disempowered.			

Figure 1-4 Data The patient/carer experience *Before*

Process

Concept	*Before* the medical Appointment)	*During* the Appointment		*After* Appointment
	Preparation	**Elicitation Phase**	**Elucidation Phase**	**After**
Process	This phase is prior to the medical appointment, when the patient/carer uses the check list to prepare for the medical history questions that will be asked. They should also prepare for the questions they have for the doctor, and reflect on the emotional state of the patient.	The involves a bi-directional conversation around the patients' medical history, including the patients' medical history, current wellbeing, present treatments/medication and so on (Cohen et al., 1995). In the region of 46% of the medical appointment consists of this stage, and is vital to the appointments' success (Bickley, 2013).	This phase of the medical appointment is when the doctor imparts and explains the diagnosis, various treatment options, self-care plans, including advice around a variety of disease management topics (Martin et al., 2014).	*After* the medical appointment the patient/carer endeavours to replays the medical appointment event to others, and to themselves, so they remember, and more importantly adhere to agreed treatment regimens (McPherson et al., 2008).

Appendix R Representative Design Principles Data

	Learnings			
Design Principle	**Practical Learning**	**Project Based Learning**	**Theoretical Learning**	**Iteration**
DP1	**Primary Data:** **Type: Interview – DS4** **Clinician 2:** *"From my experience as long as we have patients who refer to a medication as the pink tablet, rather than its chemical, generic or trade name, my job is going to be that bit more challenging. I need something that helps/functions in this regard".* **Appointment Experience:** Has worked as a clinician for 36 years. **Type: Workshop: - DS5** **Carer 2:** *"From my experience it's more important that something does what it's meant to do, rather than simply looking good."* **Appointment Experience:** Has attended approx. 57 medical appointments.	**Primary Data:** **Type: Interview – DS2** **Patient 1:** *" I need something that helps me remember my medical history".* **Appointment Experience:** Has attended approx. 272 medical appointments. **Type: Workshop – DS5** **Clinician 1:** *"Users will need to learn the function of this memory aid, where they become experts in notetaking /brevity, whilst avoiding the omission of essential medical information".* **Appointment Experience:** Has worked as a clinician for 25 years.	**Literature DS6:** *"People function through their use of two kinds of knowledge: knowledge of and knowledge how"* (Norman, 2013, p.64). Clear and concise objective/function are paramount to success (Simmons & Chew, 2015; Schwesinger, 2010; Gawande, 2010). Form follows Function (Lidwell, 2003). *"Utilitas"* or function is the first requirement of a good design (Vitruvius, 1960). Signifiers indicate things, in particular what behaviours are possible and how/when they should be done, they must be easy to grasp, or else they/intervention will fail to function as intended. (Norman, 2013).	**V1**

	Learnings			
Design Principle	**Practical Learning**	**Project Based Learning**	**Theoretical Learning**	**Iteration**
DP2 & DP3	**Primary Data:** **Type: Workshop** – **DS5** **Clinician 1:** *"We tend to group/categorise according to human physiological/clinical systems i.e., respiratory, renal etc".* **Appointment Experience:** Has worked as a clinician for 25 years. **Patient/Researcher:** *" From my experience it will need to make logical sense to patients/carers, in terms of their expectations. The last thing I want is to confuse them or make things worse".* **Appointment Experience:** Has attended approx. 196 medical appointments. **Carer 1:** *"Certain information is captured throughout the appointment".* **Appointment Experience:** Has attended approx. 64 medical appointments.	**Primary Data:** **Type: Workshop** – **DS5** **Clinician 1:** *"We could categorise according to the narrative patterns within the medical appointment".* **Appointment Experience:** Has worked as a clinician for 25 years. **Type: Workshop** – **DS5** **Patient/Researcher:** *"So I identified the "killer items" that patients or carers not only struggled to remember, but have to recall/capture during the elicitation and elucidation phases of their appointments".* **Appointment Experience:** Has attended approx. 196 medical appointments.	**Literature DS6:** Explicit categorisation increases memory recall (Kessels, 2003; Safeer, 2005). Memory recall is improved by *"chunking"*; where low-level sub- fragments of data are joined together into larger high-level significant units (Miller, 1956). The design must always be consistent, where usability and learnability advance when comparable components have a consistent appearance and function in similar way (Nikolov, 2017). Components that fit together can be visually categorised by position shape or colour (Schwesinger, 2010). To improve understanding and recall, one needs to be explicit, prioritise and encapsulate the major data points (Jansen, 2008).	**V1**

	Learnings			
Design Principle	**Practical Learning**	**Project Based Learning**	**Theoretical Learning**	**Iteration**
DP4	**Primary Data:** **Type: Workshop** – **DS5** **Clinician 1:** *"Why not structure the check list according to the clinical workflow of the medical appointment that we are trained to follow"?* **Appointment Experience:** Has worked as a clinician for 25 years.	**Primary Data:** **Type: Interview** – **DS3** **Patient 6:** *"With everything so well laid out in the check list, I really felt I could cope a lot better and that it was easier to remember stuff".* **Appointment Experience:** Has attended approx. 132 medical appointments. **Type: Workshop** – **DS5** **Patient/Researcher:** *"The check list seems to have become "self-revealing".* **Appointment Experience:** Has attended approx. 196 medical appointments.	**Literature DS6:** Structuring of information not only augments human comprehension, but additionally it serves as an effective memory recall/information retrieval instrument (Ackermann et al., 2016). The more structure individuals can put on information received through their senses, the better their recall will be (Mandler, 1967). The clinical workflow of the medical appointment is the step-by-step data assembly/direction procedure that a clinician engages in at a medical appointment (Sarkar et al. (2011). Information appears easier to encode into memory when it is structured in a way that assists the recipients' organisation of it (Langewitz et al., 2015).	**V1**

	Learnings			
Design Principle	**Practical Learning**	**Project Based Learning**	**Theoretical Learning**	**Iteration**
DP5	**Primary Data:** **Type: Interview – DS4** **Clinician 2: "***Patient reactions can be very diverse, there are times when a change intended to improve usability may benefit one patient and yet hinder another, it of course often depends on the environment they find themselves in".* **Appointment Experience:** Has worked as a clinician for 36 years. **Type: Workshop - DS5** **Researcher/Patient: "***It will be vital that the artefact does not interfere in the important dialogue between CF patient /carer and the doctor within the medical appointment".* **Appointment Experience:** Has attended approx. 196 medical appointments. **Carer 2:** *"It must be sturdy, self-supporting, as we never have any surface to write on".* **Appointment Experience:** Has attended approx. 57 medical appointments.	**Primary Data:** **Type: Interview – DS3** **Carer 3:** *"My son who is 13 years old can fill it out". "My 13-year son was surprised that the interface was not digital, an app would be able to tell me more over time, the sheet can't do this".* **Appointment Experience:** Has attended approx. 52 medical appointments. **Patient 5:** "*I used to take notes on the phone, but this is so much better".* **Appointment Experience:** Has attended approx. 156 medical appointments. **Type: Workshop - DS5** **Clinician 1:** *"Folks this isn't working for me, I can't hold a conversation with a patient like this, waiting for them to get their heads out of their phone. I have other patients to see. This is taking far too long".* **Appointment Experience:** Has worked as a clinician for 25 years. **Carer 1:** *"Perhaps we should put in instructions in each section to guide what needs to be completed before and during the medical appointment"*? **Appointment Experience:** Has attended approx. 52 medical appointments.	**Literature DS6:** Poor usability detracts from user experience (Johnson & Finn, 2017). Design must be consistent, where usability and learnability advance when comparable components have a consistent appearance and function in similar way (Nikolov, 2017). Complexity results in stress, hence a check list should be easy to read, understand and to fill out (Weiser et al., 2010). *"The focus on aesthetics may blind the designer to the lack of usability"* (Norman, 2013, p.98). Recall is affected by the form that the information is delivered, and the patients' expectations (Martin et al., 2014). The human codification process also occurs through the relationship of that information to the medium itself (Schwesinger, 2010).	**V1**

	Learnings			
Design Principle	**Practical Learning**	**Project Based Learning**	**Theoretical Learning**	**Iteration**
DP6	**Type: Interview – DS4** **Clinician 1:** *"Sometimes I don't even realise I'm using technical words. I think this is a challenge for all doctors. Having said that some patients understand a great deal regarding their condition. Time is probably the greatest challenge in ascertaining a patients/carer understanding of a term/concept or indeed explaining same to them. From my experience just keep it very simple, and remember to account for those with a lower educational background."* **Appointment Experience:** Has worked as a clinician for 25 years. **Type: Workshop – DS5** **Carer 2:** *"I always found that I best understood something if the doctor used words that I understood, or at least went to the trouble of explaining what a word or technical term meant, that way I found it easier to remember what he/she said"* **Appointment Experience:** Has attended approx. 57 medical appointments.	**Primary Data:** **Type: Interview – DS3** **Carer 11:** *"It triggers questions and other pieces of information, that I can now ask or write down and ask later in the appointment".* **Appointment Experience:** Has attended approx. 44 Medical appointments. **Type: Workshop – DS5** **Clinician 1:** *"The use of short, simple, not overly technical words that are easily understandable will work best I feel".* **Appointment Experience:** Has worked as a clinician for 25 years. **Researcher/Patient:** *"It would be great if we could use words that also act as cues or prompts as well, I have often found that certain words evoke or help me recalling".* **Appointment Experience:** Has attended approx. 196 medical appointments.	**Literature DS6:** Health literacy is fundamental to the comprehension of imparted health information, and is also vital in a patient's ability to remember medical information (Ley, 1988). Health literacy proficiencies are not static, and often depend on the status of a patient's medical condition or stress levels (Martin et al., 2014). Not surprisingly, individuals with poor health literacy are reported to have inferior health status and clinical outcomes compared to those with adequate health literacy (Martin et al., 2014). Interactions are reported to be more fruitful when doctors and patients/carers draw from a shared lexicon (Doak et al., 1996; 1998). One should use "*living room language*," or communication that utilises short, simple, non-medical words that are easily understandable (Davis et al., 2002). Words conveying value such as *"excessive"* and *"regular"* can be quite challenging for patients/carers to comprehend, especially in cases where they were not provided with related contextual information (Doak et al., 1998).	**V1**

	Learnings			
Design Principle	**Practical Learning**	**Project Based Learning**	**Theoretical Learning**	**Iteration**
DP7	**Primary Data:** **Type: Workshop – DS5** **Clinician 1:** *"The Check lists that I am familiar with or quite plain, often black and white or two toned. The WHO surgical check list is green and grey".* **Appointment Experience:** Has worked as a clinician for 25 years. **Patient/Researcher:** *"I have always found that colour catch's my eye, and draws me in. I know from reading and because my father was a bee keeper, that plants use their colours to attract insects such as bees to enable pollination".* **Appointment Experience:** Has attended approx. 196 medical appointments.	**Primary Data:** **Type: Interview – DS3** **Patient 3:** *"I find the use of colour to separate the sections really adds to the usability, making it more logical"* **Appointment Experience:** Has attended approx. 180 Medical appointments. **Patient 5:** *"I think the colour coding is great as it helps reduce stress of finding one's way back to a section".* **Appointment Experience:** Has attended approx. 156 Medical appointments. **Carer 4:** *"The pink colour is brilliant; each time I used the sheet I didn't forget to ask my questions. This really helps reduce revisits and stress".* **Appointment Experience:** Has attended approx. 38 Medical appointments. When all 18 were asked to rate the benefit of the colour (from a usability perspective) from 1 to 5 on a Likert scale where 1 it made no difference to my use of the check list, to 5 it was very useful; 12 gave a rating of 5, 5 gave a rating of 4, and 1 gave a rating of 3/5.	**Literature DS6:** Colour operates as a potent data conduit within human cognition, taking hold of attention, via visual stimuli, where an entity can seizes our interest (Bundesen et al., 2005; Wolfe, 1994). The more thought given to a tangible stimulus the greater the likelihood that an entity will be encoded in long-term memory storage (Sternberg et al., 2009). The role played by colour in augmenting our attention level is conclusive (Pan, 2012; Eysenck, 2009) as colours have an ability to attract our attention (Farley et al., 1976). The human eye is organised to emphasise the perception of edges and contrast, such contrast extractions seem to be related to *"pleasing the eye"* (Maiochhi, 2015, p.30). Avoid the use of unnecessary colours in check lists (Gawande, 2010).	**V2**

	Learnings			
Design Principle	**Practical Learning**	**Project Based Learning**	**Theoretical Learning**	**Iteration**
DP8 & DP9	**Primary Data:** **Type: Workshop – DS5** **Clinician 1:** *"Patient recall is fundamental to effective disease management, be it remembering medical histories, to remembering to take medications as prescribed."* **Appointment Experience:** Has worked as a clinician for 25 years. **Carer 1:** *"Trying to remember everything from appointments, symptoms, medications etc is very challenging, especially when you have so much other stuff going on as well. I have a job, other children and a house to run. I find the whole thing overwhelming at times."* **Appointment Experience:** Has attended approx. 64 medical appointments. **Carer 2:** *"It's so easy to mix-up appointment details they can be so alike...".* **Appointment Experience:** Has attended approx. 57 Medical appointments.	**Primary Data:** **Type: Interview – DS3** **Patient 4:** *"There seems to be a box for everything that I need to remember or record in the appointment."* **Appointment Experience:** Has attended approx. 250 Medical appointments. **Patient 3:** *"Remembering to do stuff is the bane of my life, the check list really helps me with this".* **Appointment Experience:** Has attended approx. 180 Medical appointments. **Carer 11:** *"I love the way I can go back to a particular appointment at the flick of a page, with all the details of the appointment there in front of me."* **Appointment Experience:** Has attended approx. 44 Medical appointments. **Patient 5:** *"The booklet is so sturdy and allows me to write on my lap with ease...".* **Appointment Experience:** Has attended approx. 156 Medical appointments. **Type: Interview - DS2** Forgetting is the most memory recall challenge, reported by 94% of carers/patients *during* the *elicitation phase* of the medical appointments.	**Literature DS6:** Information retrieval/memory recall observed in patients *during* the *elicitation phase* is very often episodic in nature where one must recall specific details of events, including those outside of the appointment setting (Martin et al., 2014). Indeed, in a study conducted by Gregory et al. (1991) they found that memories of an event change over time. Recent events are better recalled than more remote ones (Rubin, 1982). Self-references are remembered better than those which do not involve the self (a challenge for carers of patients) (Conway et al., 1996). Autobiographical memory has a high probability of being in error, where dating is found to be based on inference, estimation and guesswork (Brown et al., 1986). It is important to consider the relationship of that information to the medium itself (Schwesinger, 2010).	**V3 & Booklet**

	Learnings			
Design Principle	**Practical Learning**	**Project Based Learning**	**Theoretical Learning**	**Iteration**
DP10	**Primary Data:** **Type: Interview – DS4** **Clinician 1:** *"We need something to incite personal reflection by the patient, to ask how do I really feel? and what is making me feel this way"?* **Appointment Experience:** Has worked as a clinician for 25 years. **Type: Workshop – DS5** **Patient/Researcher 2:** *"We must retain the sense of "energetic and not excessively serious so that it does not become another mind-numbing form."* **Appointment Experience:** Has attended approx. 196 medical appointments.	**Primary Data:** **Type: Interview – DS4** **Clinical Psychologist:** *"I think the smiley 'Likert' that you have currently is great to check in with present mood".* **Appointment Experience:** Has worked as a clinician Psychologist for 12 years. **Type: Interview – DS3** • 9/11 CF carers embraced and welcomed the introduction of the emotional state section, since it got them to look beyond the physical manifestations of the disease, and to be more cognisant of their child's mental disposition. • 4/7 CF patients said they completed this section of the check list. Completing the Likert scale was not an issue for any of the seven patients. • *"What is making you feel this way?"* – This question raised concerns with 3/7 CF patients, as the answer to the question was deemed to be extremely private. Moreover, they felt that the check list in its current form was not physically secure enough to prevent family/others from gaining access (accidentally or otherwise) to their inner-most thoughts.	**Literature DS6:** Stress effects our ability to remember and has significant associations between physical and mental health (Quinter et al., 2016). The very context of the medical appointment itself act as a source of stress to both patient and carers, making doctor-patient communication challenging (Ong et al., 1995). Anxiety levels are reported to hinder information retrieval/memory recall (Kessels, 2003; Jansen, 2008; Safeer, 2005; Ley, 1979). *"Numerous cognitive-behavioural interventions have been developed that aim at fostering a range of social and emotional competences that serve to improve adherence"* (Martin et al., 2014, p.423). The PHQ-9 and GAD-7 questionnaires (often including Likert scales) (Quittner, 2016) and are used by clinics to screen patients for psychological symptoms.	**V3**

DP 10 continued …

	Learnings			
Design Principle	**Practical Learning**	**Project Based Learning**	**Theoretical Learning**	**Iteration**
DP10		**Type: Interview – DS3** • While these three patients agreed that a section for emotional state in a check list is very important, they also concurred that the forum must guarantee information security. • 4/7 CF patients felt it was wonderful to have a medium to express their thoughts and to self-reflect. Confidentiality was not a factor for these patients. Indeed, they felt it was/is healthy to capture and share feelings with others, to help them understand what it's like having/living with CF. **Patient 2** *"People need to know what it's like being me"*. **Appointment Experience:** Has attended approx. 96 medical appointments.	**Literature DS6:** It is well established that self- observing, the deliberate act of self-examination, aids self-control in many diverse domains (Duckworth, 2019). "*A patient's emotional response to illness might include denial that he or she is even ill, and this can be an impediment to clear communication about adherence and to accurate assessment"* (Martin et al., 2014, p.379). In a survey by Cramer (1991) 7% of patients cited emotional factors for not taking their medications, whilst 30% referred to forgetfulness.	**V3**